Clinician-Perceived Bridges and Barriers to Parental Implementation of Picture Exchange Communication System (PECS): An evaluation.

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Abstract

Picture Exchange Communication System (PECS) is an augmentative and alternative communicative system that improves communication and decreases problem behaviors in children with Developmental Disabilities and Autism. The mediator model is a validated approach that clinicians use to train parents to perform evidence-based interventions. Parental non-adherence to treatment recommendations is a documented problem. This qualitative study investigated clinician-perceived factors that influence parental adherence to PECS recommendations. Three focus groups (n=8) were conducted with Speech Language Pathologists and Behavior Therapists experienced in providing parents with PECS recommendations. Constant comparison analysis was used. In general, clinicians believed that PECS was complex to implement. Thirty-one bridges were identified to overcome complexity. Twenty-two barriers and 6 other factors also impacted parental adherence. Strategies to address these factors were proposed based on a review of the literature. Future research will be performed to validate these findings using parents and a larger sample size.

Key Words: Autism Spectrum Disorder, Picture Exchange Communication System, Mediator Model, Parent Training, Parental Adherence.

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Introduction

Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) is a form of Augmentative and Alternative Communication (AAC) that is effective at enhancing communicative competence for individuals with Developmental Disabilities (DD) and Autism Spectrum Disorder (ASD) who present with challenging communication impairments (Millar et al., 2006). For the purposes of this study, DD will be defined by the Ontario Bill 77 definition, which is impairments in one's cognitive and adaptive functioning (Bill 77, Services for Persons with Developmental Disabilities Act, 2008). ASD are pervasive developmental disorders characterized by impaired functioning across multiple domains including social interactions, communication and repetitive and restrictive behaviors (Diagnostic and Statistical Manual of Mental Disorder-IV TR, 2000).

PECS is often used to teach functional communication to individuals with DD and ASD. It relies on principles of Applied Behavior Analysis (ABA). Distinct prompting, shaping, reinforcement and error correction procedures are specified at each training phase, consequently increasing independent requests (Bondy & Frost, 1994). PECS involves 6 phases that progressively teach functional communication and improve a child's vocabulary. PECS improves communication by allowing a child to make requests, comment, and ask questions, which can reduce maladaptive behaviors (Frost & Bondy, 2002).

To improve the communication of individuals with DD and ASD, clinicians such as Speech Language Pathologists (SLPs) and Behavior Therapists (BTs) use the mediator

model to train families to implement PECS in the home environment. In this model a specialist provides parents with clinical recommendations and training in child assessment and intervention strategies. Parents are expected to implement the recommendations and strategies correctly and consistently. The specialist provides the parent with feedback to ensure parental adherence to the recommendations (Vernberg & Reppucci, 1986). Sheridan and Kratochwill (2007) discuss this model as one that trains parents in the child's intervention and serves in the role of the mediator, empowering parents to become involved in their child's services. Studies have demonstrated that by training parents with the mediator model, there can be clinically significant improvement in child outcomes (Elder et al., 2005; Hemmeter & Kaiser, 1994; Kaiser et al., 2000; Koegel et al., 2002; Laski et al, 1998; Stiebel, 1999; Vismara et al., 2009). Professional organizations recognize the importance of the mediator model and incorporate this model in their standards of practice. In 1989, the American-Speech-Language-Hearing Association (ASHA) released a statement advocating for SLPs involved in AAC delivery to include family involvement in interventions.

There is emerging evidence to support the use of the mediator model and PECS. Studies have investigated training parents (Chaabane et al., 2009), group home staff (Barnes et al., 2011; Wood et al., 2007), university students (Rosales et al., 2009) and teachers (Howlin et al., 2007). These studies have demonstrated that previously untrained mediators can adhere to recommendations and effectively deliver PECS. In Ontario, the mediator model is a common method of service delivery for PECS implementation.

There has been minimal research identifying barriers among parents and clinicians to implementing an AAC and adhering to the recommendations in the home

setting. However, numerous studies have investigated parental adherence to behavioral treatment recommendations. These studies have identified a number of child, parental and clinician factors that impact parental adherence (Allen & Warzak 2000; Green, 2007; Moore & Symons, 2011; Isaacs et al., 2008; Symon, 2005). Child factors include challenging behavior and stereotypy. In such cases, parents might have trouble following through on recommendations because they have to address or escape from the child's behavior. Parental factors include time constraints, cost of training, parental cognitive impairment, restricted economic resources, social isolation and skill complexity. Green (2007) suggests that parents are more likely to implement interventions if the intervention is "easy to use, requires little time, and is widely accepted" (Green, 2007). Complex interventions become even more difficult to adhere to when parents lack understanding due to cognitive or psychiatric impairment. Clinician factors include clinician education, experience, training technique, and pre-conceived notions. Studies demonstrate that sound instructional strategies using instruction, modeling, rehearsal and feedback facilitate parental adherence (Allen & Warzak, 2000; Lang et al., 2009). Although this literature refers to behavioral recommendations, similar findings should be expected in the adherence to PECS recommendations.

This research suggests there may be several factors that contribute to parental and clinician implementation of PECS intervention for individuals with DD and ASD. Andrews & Andrews (1990) argue that in order for an intervention to be successful, it needs to be congruent with the family dynamics. Despite this acknowledgment of family led intervention, current research mainly focuses on family participation during the decision making process, rather than parental implementation of an AAC in their home

setting (Beukelman & Mirenda, 2005; McNaughton, 1990). Furthermore, despite increasing parental involvement in speech interventions, parents have not expected to take on the primary role of language facilitation during treatment (Tempel et al., 2008).

Clinicians remain in primary control over the direction of a child's intervention, resulting in a therapist-oriented approach (Pappas et al., 2008). There is growing evidence supporting a transition to parents as primary facilitators of treatment. Empirical research is needed to understand the barriers to parent implemented intervention from the perspective of parents and clinicians in order to understand adherence and the problem of non-adherence.

The objectives of this study are: (a) to use focus groups to investigate the factors that contribute to parental adherence and non-adherence of PECS intervention and (b) to develop recommendations to enable consultants and parents to improve implementation of PECS.

Literature Review

Developmental Disability/Autism Spectrum Disorder

The term Developmental Disability (DD) will be used in this thesis to describe pervasive cognitive and adaptive deficits. The Diagnostic and Statistical Manual 4th Edition (Text Revision) (DSM IV-TR, 2000) uses the term Mental Retardation (APA, 2000) to describe the condition associated with these deficits. However, the term Mental Retardation is considered pejorative by many consumer groups and families, and is used pejoratively in pop culture. Other terms have been used in recent years in laudable efforts to reverse marginalization. The term DD has been used widely in Canada. For

example, in Ontario, Bill 77 legally defines DD as limitations in one's cognitive and adaptive functioning beginning before 18 years of age and which will likely persist for the duration of one's life. The Bill describes these limitations as ones that affect major life skills including language, learning, personal care, and the ability to live independently (Bill 77, Services for Persons with Developmental Disabilities Act, 2008). Similarly, the American Association of Intellectual and Developmental Disabilities (AAIDD; AAIDD, 2012) defines ID as a condition that involves significant limitations in intellectual functioning and adaptive behavior, including conceptual, social and practical skills. For the purposes of this thesis, the term DD will be used, as it is most consistent term used in the literature that has been reviewed. The Statistics Canada Participation and Activity Limitation Study (2006) identified increasing incidence of all forms of disability among children. The study identified 1.2% of Canadian children under age 5 and 3.2% of children aged 5 to 14 as having a chronic condition that included DD and ASD. DD and speech impairment were specifically identified in 53,740 and 78,240 Canadian children respectively (Statistics Canada, Participation and Activity Limitation Survey 2006: Analytical Report, 2006). ASD includes impairments across multiple domains. The American Psychiatric Association Diagnostic and Statistical Manual of Psychiatric Disorders Fourth Edition (DSM-IV-TR) (2000) defines the three main criteria for the diagnosis of ASD as impairments in social interactions and communication, and restrictive and repetitive patterns of behavior, interests and activities"(Diagnostic and Statistical Manual of Mental Disorder-IV TR, 2000, p. 75). The manual states that these impairments must begin before age three and cannot be caused by another diagnosis that better accounts for the symptoms (Diagnostic and Statistical Manual of Mental Disorder-

IV TR, 2000). Studies suggest that Autism incidence is increasing. Although not representative of the entire United States population, the CDC reported ASD prevalence in fourteen Autism and Developmental Disabilities monitoring sites as 11.3 in 1000 (range: 4.8 to 21.2 per 1000) or one in 88 children (Centers for Disease Control and Prevention, 2012).

Individuals With Developmental Disabilities Have Increased Speech Impairments

Many individuals with DD including ASD struggle with the inability to communicate effectively and functionally (Sigafoos, 2001). Individuals with DD and ASD frequently develop language later and at slower rates compared to their typically developing peers (Siller, 2002). Individuals with DD and ASD often have specific communication deficits that may represent linguistic impairments or motor speech impairments such as aphasia, dyslexia, apraxia, dysarthria (Strand, 2008). Furthermore, when speech is present in children with DD and ASD, it is frequently in the form of a mand and/or an echoic. A mand is defined as a request where the verbal response is maintained because of its direct reinforcement for the child, and an echoic is defined as vocal imitation. Children with DD and ASD often experience other preverbal deficits that further prevent functional communication. These deficits include initiating joint attention, understanding gestures and maintaining eye contact (Siller, 2002).

Communication impairments often result in current and future problem behaviors, disrupting the lives of these individuals and their families (Sigafoos, 2006). Children with communication deficits are more likely to become dependent for longer, place more demands on their parents in comparison to typically developing children, and require

higher levels of support from other individuals (McCubbin, 1982). A lack of inclusion into the community and difficulty initiating social interactions are characteristics typically experienced by children with DD and ASD who have communication impairments (Sigafoos, 2006). Given that individuals with DD experience prevalent communication impairments, often leading to additional challenges, they are regular candidates for Augmentative and Alternative Communication (AAC) (Millar et al., 2006).

According to Mirenda and Erickson (2000), in order for communication to be functional, it requires understanding through both familiar and unfamiliar communicative partners. Given this, an AAC that is easily understood by both the communicator and the listener is crucial for developing functional communication.

Augmentative and Alternative Communication Systems and Other Modalities

AAC are used to supplement speech in individuals who are unable to communicate functionally. There are many types of AAC intervention strategies that clinicians may select for their client. Systems can be gestural, graphic, picture exchange, direct selection, direct instruction, activity-based or speech generating. Systems can be manual or electronic (Millar et al., 2006). AAC are either aided or non-aided. Aided systems are external to the users body compared to unaided systems which requires nothing other than the users body parts to convey a message (Fuller et al., 1997). Examples of aided systems are pictures, photographs and real objects, while unaided systems include facial expressions, speech, or body expressions (Mirenda, 2001).

Clinicians perform a detailed assessment prior to selecting an AAC device that is most functional and interactive for their client. Ideally, BTs work closely with SLPs who are qualified to perform communication assessments to recommend the most appropriate AAC for an individual. In many cases, however, BTs often teach an AAC, such as PECS, while a family waits to access services from an SLP or as part of functional communication training.

Research shows that AAC systems for individuals with DD who have severe communication disorders enhance communicative competence and facilitate the development of language skills (Millar et al., 2006). The goal of AAC interventions is to assist individuals with severe communication disorders to become communicatively competent in order to meet their current communication targets. These targets can be generalized to prepare them for their future communicative goals (Mirenda, 2001). AACs facilitate an individual's ability to expressively and receptively communicate. Millar et al., (2006) conducted a literature review of 23 studies involving a total of 67 participants demonstrating that 89% of the cases resulted in positive treatment effects for individuals aged 2-60 with DD through the use of an AAC. Of the studies reviewed, 61% investigated unaided AACs while 31% investigated non-electronic aided systems. This study demonstrated that speech gains can be acquired through AAC systems for a variety of age groups.

In addition to augmentative communication strategies, alternative strategies exist. Speech imitation training, sign language, and picture-point systems are all communication modalities that clinicians have implemented with children with Autism. These communication modalities require prerequisite skills.

Speech imitation training (or echoic training) involves child imitation of speech sounds to ultimately develop functional speech. Speech imitation training depends on attending skills, eye contact, gross motor imitation, oral motor imitation, and word imitation. Typically developing children develop speech through speech imitation and social reinforcement that follows each speech imitative behavior. Many children with DD and ASD initially do not have attending skills such as sitting appropriately and initiating eye contact with the communicative partner. Additionally, many children with DD and ASD do not respond solely to social reinforcement consequences, and it therefore takes children with DD and ASD longer to develop functional speech using speech imitation training.

Sign language is another communication modality. Children are taught to imitate signs made by a trainer in order to ask for or label particular items. Many children with DD and ASD have fine motor deficits, making the use of sign language difficult. Sign language is not a universal modality because it cannot be understood in all settings. Furthermore, sign language is not generalizable to the public community, eliminating multiple potential communicative partners.

Another AAC strategy is picture/symbol system where the user learns to point to a picture to communicate. This method might be challenging because it requires discrimination skills where the child has to scan all pictures and be able to point to the one that he/she wants (Frost & Bondy, 2002).

Research provides evidence that children with DD and ASD benefit greatly when language input is augmented with a visual modality (Ganz & Simpson, 2004; Hamilton &

Snell, 1993; Hodgdon, 1995; Keen et al., 2001; Mirenda & Santogrossi, 1985; Rowland & Schweigert, 2000). The behavioral intervention program known as the Picture Exchange Communication System (PECS) is an AAC device that successfully uses aided pictorial symbols to improve the development of speech for individuals with DD with severe communication impairments (Charlop-Christy et al., 2002; Kravits et al., 2002).

Picture Exchange Communication System

Bondy and Frost (1994) developed PECS for the Delaware Autistic Program to teach 85 two-year-old children with Autism and other social communicative disorders to make requests to ultimately acquire the skills to communicate independently in social contexts. Initially, these children either did not speak, had echoic speech, only spoke when prompted, or only produced speech in socially unacceptable ways including self-stimulatory behavior through scripting. Following the children over 5 years, 76% of children placed on PECS either produced speech or developed speech augmented by the picture system (Bondy & Frost, 1994). The key component and prerequisite to beginning PECS is the motivation of the user. The motto of PECS is to "teach to the reach". This implies that the user indicates what is reinforcing to them by pointing to, moving towards, or reaching for a specific object, item or person (Frost & Bondy, 2002).

Unlike the aforementioned communicative modalities, Frost and Bondy (2002) describe PECS as adaptable and explain that the user does not require prerequisite skills to communicate. Children do not need requisite fine motor skills and PECS techniques can be adapted to compensate for weak grip by using cardboard or glue on the PEC.

There is no requisite developmental age and children do not need to understand the meaning of pictures before implementation. Children do not need to have mastered eye-to-eye contact, attentive sitting, and response to questions or object matching. The system does not require the communicative partner to be familiar with an additional language. PECS is low cost, portable and is suitable for many settings. Most importantly, the user does not have to be nonverbal to benefit from PECS (Frost & Bondy, 2002). PECS incorporates functional communicative responses that promote meaningful interactions between the environment and the child (Bondy and Frost, 1994).

PECS involves 6 phases that progressively teach functional communication and improve the user's vocabulary. Phase 1 teaches users how to communicate by reaching for a single picture and exchanging it with a communicative partner for a functional reward. A back-prompter is a second individual positioned behind the user who ensures the user exchanges the PEC correctly to their partner. Phase 2 enforces persistence and distance by using a backward chaining format to fade out the back-prompter and communication partner. Backward chaining involves breaking a complex sequence into small steps and teaching in a step-wise manner with the last step first. This phase generalizes skills learned in phase 1 by increasing the distance between book and communication partners and also by introduction of new communicative partners. Phase 3 involves picture discrimination between preferred and non-preferred pictures. It involves conducting correspondence checks to ensure the user is requesting what they really want. The goal of Phase 4 is to build simple sentences using "I want" PEC and placing it on the sentence strip. Phase 5 and 6 expand attributes and language vocabulary by adding adjectives, verbs and nouns. Phase 5 teaches users to answer questions while

phase 6 teaches users to comment. These 6 phases embrace specific principles of ABA such as reinforcement, and adapting training techniques based on collected data to emphasize the development of functional communication skills (Frost & Bondy, 2002).

PECS relies on principles of ABA including distinct prompting, shaping, positive reinforcement, broadening stimulus control and setting events, errorless teaching, and error correction. These principles are intimately incorporated throughout all 6 training phases. Additionally, PECS incorporates B.F. Skinner's verbal operants, which are central to ABA. There are 4 main verbal operants defined by antecedent and consequential factors that are all central to PECS usage. A mand is a verbal operant "in which the response is reinforced by a characteristic consequence and is therefore under the functional control of relevant conditions of deprivation or aversive stimulation" (Skinner, 1957, p. 35-36). A tact "evoked by a particular object or event or property of an object or event (Skinner, 1957, p. 82). Tacts occur due to the environmental objects or events. An example of manding and tacting occurs in PECS phase 1 where the communicative partner labels the item (tacting) and then immediately provides the functional reward requested (manding and positive reinforcement). Furthermore, phase 4 involves autoclitic operants which are under the control of the speakers own verbal behavior (Skinner, 1957). For instance, the use of the "I want" PEC develops an autoclitic frame. Phase 5 and 6 include the use of intraverbal operants that are verbal behavior under the stimulus control of other verbal behavior (Skinner, 1957). For example, in phase 5 when asked "what do you want?" the response of the user is partially under the control of the communicative partners question. All 6 phases of PECS deeply rely on the

principles of ABA in order to successfully develop functional communication (Frost & Bondy, 2002).

Picture Exchange Communication System (PECS) emphasizes teaching a child to initiate requesting for seen and unseen items, to respond to questions, and to make social comments and labels. The literature suggests that PECS are effective in improving speech impairments. Charlop-Christy et al., (2002) conducted a study to empirically assess the utility of PECS with children with ASD using a multiple baseline design across participants. All 3 children met criterion for each phase of PECS and were able to ask questions and comment before program completion. The focus of vocal and pictorial mands in PECS contributes to the initiation of communication that is functional for children with autism. Charlop-Christy et al., (2006) suggest that PECS reduces and prevents problem behavior by allowing the children to be able to communicate their requests, while increasing their social and communicative behaviors. Using PECS, children learn to initiate access to reinforcers in their environments; therefore, motivating operations help to promote childrens' desire to communicate (Garrison-Harrell et al., 1997). Overall, PECS frequently results in the development of communication that is functional for children with ASD because it requires fewer fine motor skills for the user, is more intelligible to unfamiliar partners and is easier for communicative partners to learn and to use (Mirenda, 2003; Rotholz et al., 1989).

Clinicians typically train children on how to use PECS. In addition, clinicians provide recommendations to parents on the appropriate use of PECS with their children. These clinicians empower parents to improve their child's communication and allow for effective communication within the home environment. Involving families in PECS

training is crucial to increase treatment effects for the child. Providing systematic step-by-step training to parents of children that use PECS is essential to maximize treatment gains. The involvement of parents as effective communicative partners in PECS ensures that PECS is used repeatedly and interactively across all environments.

Mediator Model

The mediator model is a contemporary approach that focuses on parental involvement within assessments and interventions of underlying processes. Parents are provided with clinical recommendations to carry out on a day-to-day basis with feedback monitoring from the therapist (Vernberg & Reppucci, 1986). These authors discuss this indirect service delivery model in depth. These authors discuss the mediator model as training others, including parents, in assessment and intervention, data collection and data-based problem solving. Sheridan and Kratochwill (2007) suggest that although teachers and peers may also act as mediators to facilitate a child's treatment, these individuals vary throughout a child's development. Contrarily, parents are continuously involved in a child's developmental transitions that enable direct parental involvement in the decision-making and monitoring progress process of the intervention throughout the child's life. Dunst et al. (1988) suggests that parental empowerment helped parents accomplish goals by developing specific assets, abilities and strengths. By empowering parents, they become motivated to develop skills that can generalize and be applied to a variety of settings. According to Allen and Warzak (2000) the effective use of the mediator model is dependent on the triad of features: "effectiveness of the intervention as demonstrated in the literature, their precise delivery by the clinician to the parent, and

adherence to or consistent implementation of the intervention" (Allen & Warzak, 2000). Parental involvement has long been used in the education system to help improve academic success and reduce problem behaviors.

Sheridan and Kratochwill (2007) summarize the importance of parental actions within the home to promote healthy child development. These authors discuss "the critical role of the natural home and community as important contexts for learning and opportunities to extend and generalize what children learn and do within the school day" (Sheridan & Kratochwill, 2007, p. 10). Henderson and Mapp reviewed 51 studies conducted between 1993 and 2002 on outcomes of parent and community involvement and intervention in student achievement. They concluded upon synthesis of the data that " there is strong and steadily growing evidence that families can improve their children's academic performance in school and have a major impact on attendance and behavior" (Henderson & Mapp, 2002, p. 24-41). This review study provides further evidence of the importance of parent implemented intervention for child success. The mediator model was discussed by behaviorists as early as the 1960s, and has become the trend in service delivery in other related fields including occupational therapy (Bayzk, 1999) and the field of communication disorders (Crais, Poston Roy, & Free, 2006).

Many studies have demonstrated that parents could be effectively trained as mediators on interventions for their children with language disorders (Elder et al., 2005; Hemmeter & Kaiser, 1994; Kaiser et al., 2000; Koegel et al., 2002; Laski et al, 1998; Stiebel, 1999; Vismara et al., 2009) and behavioral deficits (Kaiser & Hancock, 2003; McConachie & Diggle 2007;Schreibman et al. 1991, Smith et al. 2000, Howlin et al. 1987). In general, these studies have demonstrated that parents can be trained through the

mediator model and that this training was socially and clinically significant in improving child outcomes.

The benefit of parents as mediators in language intervention is well documented. Elder et al. (2005) trained 18 fathers of children with Autism to implement imitating and waiting interventions within the home environment. The father-training intervention contained the imitating component, where the fathers exaggerated the child's behavior within 5 seconds, promoting play interactions. Additionally, during the waiting component, the fathers prompted the child and waited 3 seconds and provided facial expressions to prompt social interaction. Results demonstrated that all fathers were able to successfully implement the intervention, which improved the children's pre-communication skills, and fathers maintained these skills at a 1-month follow up. Kaiser et al. (2000) trained 6 mothers of children with Pervasive Developmental Disorder Not Otherwise Specified to implement enhanced milieu teaching through behavioral skills training. Findings demonstrated that the parents' ability to implement this intervention was effective and generalized from the university setting to the home environment. In addition, the parents' ability to implement this intervention was maintained at a 6-month follow-up. Koegel et al, (2002) trained 9 parents of children with Autism to implement Pivotal Response Training (PRT) using verbal and written instructions, role-playing and feedback. Results indicated that all parents' implemented PRT 100% correct which was maintained from 3-12 months. In addition, Vismara et al., (2009) trained 6 parents implement the Early Start Denver Model with their children with Autism. Implementation of this model increased across all parents and was maintained for 3 months. Furthermore, the results of a large metaanalysis of 11 studies involving 60

parents trained as mediators demonstrated that majority of parents implemented communication interventions with fidelity after being trained (Lang et al., 2009). Previous studies have investigated and demonstrated that parents as mediators can implement communication and behavioral interventions effectively. According to the National Research Council (2001), interventions delivered by parents, are demonstrated to be effective and are crucial to increase the success of intervention programs for children with ASD.

Similarly, there is existing evidence supporting the use of mediators in behavioral intervention. McConachie and Diggle (2007) performed a systematic review on the impact of parent implemented intervention on children with Autism, identifying 439 articles discussing parent training in Autism, including four randomized control trials and eight controlled trials. Upon synthesis of the data, these authors found that parent led intervention improved child communication behavior, improved parent child interaction and decreased general behavior problems (McConachie & Diggle, 2007). Howlin et al., (1987) reported on the key early findings of training parents as co-therapists in the treatment in children with ASD. These authors compared home-based training of 16 boys with ASD where parents served as mediators to a control group of 16 boys with ASD who received only intermittent outpatient care in medical and educational facilities. The parent training involved teaching parents to perform functional analysis, decide on a course of action and note their success to a variety of communication and behavioral interventions. Results indicated that children in the parent training arm had greater improvements in their use of speech, were more socially responsive, showed more

flexible social play, had fewer tantrums, and had less ritualistic behavior (Howlin et al., 1987).

In 1989, The American-Speech-Language-Hearing Association (ASHA) published a statement of the roles of a Speech Language Pathologist (SLP) involved in AAC service delivery. Among the responsibilities, several addressed the importance of family involvement in interventions. Current practices focus on family participation during the decision making process, assessment and intervention of their child. It is understood that parental involvement is crucial to ensure better treatment outcomes for the child (Beukelman & Mirenda, 2005; McNaughton, 1990). The success of an AAC intervention is becoming increasingly dependent on the families involvement as it is linked to developing literacy skills for the child (Angelo et al.,1995; Koppenhaver et al.,1991; Marshall & Goldbart, 2008).

The Effectiveness of Parental Involvement in Communication Intervention

For young children, parents are the lead natural source of language instruction (Kaiser & Hancock, 2003). Further, as the people who typically spend the most time with children, it is essential that they play a pivotal role in language instruction. Studies have examined the effectiveness of parent implementation of communication interventions in the naturalistic setting. Stiebel et al., (1999) trained parents of 3 children with Autism to implement Natural Language Paradigm including the use of picture cards through instructions and role-play. The results indicated that the children learned to use their picture cards symbols independently and spontaneously after parental training. Also, Elder et al., (1995) trained 4 mothers of children with Autism to implement speech

imitation interventions using instructions and role-play. The results indicated that vocal utterances increased in all children. Similarly, Koegel, et al. (2002) trained 9 parents of children with Autism to implement pivotal response training using instructions, role-play and feedback. Results indicated that 4 out of 5 children increased frequency of expressive verbal responses. The remaining child showed gains at the 12-month follow up. In addition, children generalized communication skills to a various contexts. Relatedly, Symon (2005) trained 3 mothers of children with Autism to implement Pivotal Response Training using instructions, role-play, feedback and discussions on how to train other caregivers. Results demonstrated children's' functional verbal language and appropriate interactions increased after training the second caregiver. Chaabane, Alber-Morgan, and DeBar (2009) investigated parental PECS improvisation training through the use of instruction, modeling, practice and feedback in two parents of children with ASD. Results indicate that parents were able to immediately and substantially increase correct improvisations.

Treatment Adherence

It is clear that parents can be effectively trained in the use of specific interventions and that these interventions positively impact child outcomes. Allen & Warzak (2000) discuss the importance of parent adherence on interventional success. Despite having effective interventions, and sound parent training, interventions will only be successful if parents adhere with treatment recommendations.

Treatment adherence is referred to as treatment integrity or procedural integrity. It is defined as the extent to which the treatment is applied exactly as recommended

without unplanned variables inadvertently confounding the treatment.

Treatment adherence is the degree to which an individual consistently follows through with a set of recommendations in the presence and absence of the trainer's direct oversight (Moore & Symons, 2011). It is crucial to include integrity checks otherwise the treatment might be administered improperly, applied inconsistently, or delivered overdosed or under-dosed. Factors that threaten treatment integrity are administering a treatment in an unfair way or treatment drift when the application of the treatment is administered differently with the progression of time (Cooper, Heron & Heward, 2007; Moore & Symons, 2011).

The majority of adherence data comes from the medical literature. Physicians have investigated parental adherence to treatment recommendations for a variety of medical conditions including asthma, diabetes and psychiatric medication usage. DiMatteo (2004) reviewed 50 years of adherence to medical treatment recommendations by metaanalysis of 569 adherence studies. The average non-adherence rate across studies was 24.8% and ranged from 4.6% to 100%. Kazdin et al, (1997) investigated barriers to psychiatric treatment for children with behavioral disorders. This study identified parental stressors, obstacles to attending treatment, poor perceptions of treatment, poor relationship between parent and therapist, socioeconomic disadvantage, younger parents, single parents, and parent history of psychiatric illness as barriers to treatment (Kazdin et al., 1997).

The majority of studies investigating parent training in ASD/DD assess treatment outcomes but fail to address intervention adherence (Allen &Warzak, 2000). The concept of non-adherence exists in the ASD literature and negatively impacts treatment outcomes

(Allen & Warzak, 2000). Moore and Symons (2009) investigated parental adherence to medical and behavioral treatment recommendations in children with ASD by paper and online survey. Families checked off if they have received and followed through with the following medical recommendations for implementation: "oral medication", "regular office visits with psychiatrist, psychologist or M.D.", "exercise or other physical activity regimen," and "modifications to diet"(Moore & Symons, 2009, p.1175). Behavioral recommendations included: "reinforcement", set-up for good behavior," (i.e., antecedent strategies), "punishment," and "not reacting to problems" (Moore & Symons, 2009, p.1175). Symons, 2009, p.1175). Mean non-adherence to treatment recommendations was 15.9% for medical recommendations compared to 24.2% for behavioral recommendations and was statistically significant. Another study by Moore & Symons (2011) investigated parental-reported adherence to 6 skill instruction and problem behavior management strategies, measured through a survey. Parents reported on average less than 80% adherence to 5 of 6 management strategies. The strategy that parents were least able to adhere to was establishing reinforcers. Parents were best able to adhere to honoring requests.

Despite the evidence to suggest non-adherence, there are observational studies that have demonstrated short and long term parental adherence to treatment recommendations. As previously mentioned, Elder et al. (2005) demonstrated parental adherence to implementing speech imitation intervention at 1-month follow up. Kaiser et al. (2000) demonstrated parental adherence to Enhanced Milieu Teaching in a 6-month follow up. The previously cited study by Chaabane et al. (2009) investigating parent implemented PECS training demonstrated high treatment integrity (97%) using a

procedural checklist on video-taped sessions. Multiple observers scored the video-taped sessions and there was 91% inter-observer agreement on implementation.

Mediator Model and PECS

It is common in Ontario to use an indirect service delivery method where parents are trained as the primary implementer of early phase PECS. Many prominent service organizations in Ontario have programs directed at parent training as assessors and implementers for a variety of interventions, including PECS. A number of studies have demonstrated that previously untrained mediators can be effectively trained using behavioral skills training to implement PECS.

Rosales et al. (2009) evaluated the effectiveness of BST in teaching PECS Phase 1-3 to three university students who were previously untrained. These authors demonstrated that these participants were able to adhere to recommendations with fidelity which was generalized and maintained. Further, these authors demonstrated that training was efficient taking less than three hours to reach mastery. Wood et al. (2007) trained four group home staff to conduct PECS phase 1 with a group home resident with DD. These four staff were able to adhere to recommendations with a minimum of 88% fidelity. Additionally, Chabanne demonstrated that parents can be mediators of advanced PECS improvisation training. These parents adhered to over 95% of recommendations and their children with ASD mastered and maintained PECS improvisation skills.

On the other hand, Barnes et al. (2011) demonstrated that three direct care staff could not adhere to PECS recommendations. They had difficulty with recommendations related to preparation and ABA principles including ensuring items were preferred,

conducting reinforcer assessments, and correctly scoring within 5 seconds. However, this study was widely criticized for not training staff using BST. Additionally, Howlin et al. (2007) was unable to demonstrate maintained improvements in child PECS use and communication. However, teacher adherence was not assessed in this study so it unclear how training affected mediator skills.

To summarize, the mediator model of PECS delivery is widely used in Ontario for early phases and there is emerging evidence to support its use. Despite this, further research is needed to demonstrate that parent-implemented PECS for early phases works and that child outcomes improve. Regardless, parents in Ontario are currently being trained as mediators for PECS and it is crucial to optimize parent adherence to PECS recommendations in the hope of improving child outcomes.

Perceived Factors Contributing To Parental Adherence

A number of investigators have identified factors that influence parental adherence. Symon (2005) discusses "communication interventions often contain multiple components and frequently require systematic and consistent implementation. Factors such as challenging behavior, stereotypy, logistical obstacles such as distance to training centre, time, cost of training may further complicate intervention" (Symon, 2005). Additionally, Green (2007) suggests that parents are more likely to implement interventions if the intervention is "easy to use, requires little time, and is widely accepted" (Green, 2007). Allen and Warzak (2000) suggest, "parental adherence to treatment is reflected in the extent to which the parent's behavior coincides with the recommendations of the training professional" (Allen & Warzak, 2000). Allen and

Warzak (2000) discuss barriers to parental adherence to treatment recommendations including parental cognitive impairment, restricted economic resources, social isolation, perceived stigma of behavioral change protocol, lack of generalizability of treatment protocol, skill complexity, poor instructional technique (Allen & Warzak, 2000). Moore & Symons (2011) used surveys to investigate parent-reported adherence to skill instruction and problem behavior management strategies in 21 parents of children with Autism. Results indicated factors correlated with parental adherence were perceived effectiveness of the intervention, perceived confidence in the success in the intervention and agreement on spouse on when/how to implement intervention. Results indicated factors correlated to parental non-adherence were total number of child problem behaviors and whether the child was currently receiving professional services. This study did not find correlation between parent education, parent marital status, number of children in the home, and child age of diagnosis (Moore & Symons, 2011). Time constraints are an additional factor that impacts parental adherence (Pappas et al., 2008). Tempel, et al., 2008 demonstrated that parents are not interested in assuming the primary role of language facilitator, which is a potential barrier to adherence.

Clinician factors have also been shown to impact parental adherence. Pappas et al., (2008) conducted a questionnaire study that was used to determine Speech Language Pathologist (SLP) beliefs on factors influencing parent training and adherence. This study concluded the involved speech therapists did feel confident with parental abilities and involved them less in the design of the treatment (Pappas et al., 2008). Angelo et al. (1995) demonstrated that when families believe that they do not have ownership of

treatment recommendations they fail to follow through on SLP recommendations. Studies demonstrate that sound instructional strategies using instruction, modeling, rehearsal and feedback facilitate parental adherence (Allen & Warzak, 2000; Lang et al., 2009).

A precursor study was conducted by Dr. Condillac and Dr. Issacs' research team (Isaacs et al., 2008) investigating factors relating to parental adherence to behavioral recommendations. This study conducted one BT focus group including ten subjects and four parental focus groups totaling seventeen parents. All participants were recruited through a government-funded agency that provides behavioral supports to people with DD and their families. Results indicated six emergent themes across parental and BT focus groups. These themes included: caregiver burden, empowerment, communication, access to services, congruity of support, and service delivery. Caregiver burden demonstrated factors relating to adherence due to the child's behavior, due to parental and BT role strain, and due to the chosen behavioral intervention. Parents discussed feeling more empowered and confident through education from BT services, in turn, promoting adherence. As a result, BTs felt empowered when parents were more confident in dealing with their child's behavior. Open and honest communication between parents and BTs was demonstrated as an essential component to promote adherence. Many parents felt that BTs did not understand their needs and concerns. Additionally, many parents and BTs expressed that language barriers served as a factor-promoting non-adherence. Both parents and BTs expressed the need for more frequent communication to contribute to better follow-through. Factors relating to adherence also included parental access to services. Parents reported long waiting lists, short service time and BTs lack of

time as factors influencing adherence. Incongruity of recommendations of professionals led to non-adherence. Service delivery was the final theme identified and included factors such as parental buy in to the mediator model and the importance for BT training techniques using modeling and observations.

The current study expanded on the line of research investigating bridges and barriers to behavioral recommendations. Unlike the study by Isaacs et al. (2008) this study's scope was specific to a particular intervention. The goal was to develop specific factors that influenced parental adherence to PECS recommendations.

Qualitative Research

Qualitative research is an inquiry process that attempts to interpret social phenomena using a naturalistic approach. Naturalistic techniques involve the analysis of empirical materials including observations, interviews, case studies, individual experiences and focus groups (Denzin & Lincoln, 2011). The goal of qualitative research is to build a holistic picture that best describes the pertinent natural environment (Cresswell, 1998). By analysis of personal experiences and first hand accounts the researcher is able to develop an in-depth representation of the phenomena being examined. Qualitative research explores, synthesizes and interprets participant experiences, feelings, behaviors, attitudes, perceptions and interactions (Pope & Mays, 2006). There are three major components of qualitative research: data collection, inductive analysis, and a narrative approach to report writing (Cresswell, 1998). Data collection requires the researcher to interact with study participants often trying to gain access and rapport to provide an "insider" perspective (Cresswell, 1998, p. 16). Inductive

analysis involves the task of synthesizing large amounts of narrative data into categories and themes that are representative of all study participants. Secondary to the naturalistic approach and analytical rigor, qualitative research requires large amounts of time and resources (Creswell, 1998). Qualitative research is susceptible to bias as the researcher can shape ideas based on their own personal values. Trustworthy analysis is performed to minimize this bias by incorporating feedback from study participants and external auditors (Guba & Lincoln, 1981).

Qualitative research often forms the foundation of larger quantitative studies. Qualitative and quantitative differ in multiple facets including research objectives, data collection technique, rigidity of methods, data analysis, data presentation and generalizability of results (Pope & Mays 2006). Qualitative research explores few cases or subjects in-depth while quantitative research has a more narrow scope explored in many subjects (Ragin, 1987). Qualitative research can be described as more descriptive, seeking to explore phenomena in detail; where as quantitative research is more evaluative, seeking to confirm pre set hypotheses. Qualitative research can present divergent participant perspectives while quantitative research summarizes all participant outcomes uniformly as single variables. Qualitative research is adaptive; research questions emerge throughout the data collection process. On the other hand, quantitative research requires an *a priori* research question that cannot change throughout the study duration (Cresswell, 2003). Deciding between qualitative and quantitative techniques requires evaluation of the nature of one's research question. Qualitative research is ideal for examining research questions exploring variables that are not easily identifiable, areas that have limited previous exploration and topics that need in-depth analysis. Three major

forms of data collection in qualitative research are participant observation, interviews and focus groups. This study used a focus group design to answer the research questions.

Focus Groups

Focus groups are one of the fundamental techniques for qualitative data collection. Krueger defines focus groups as people assembled in a series of groups, possessing certain characteristics, providing data of a qualitative nature in a focused discussion (Krueger, 1994). Focus groups involve semi-structured group discussion between researcher and participant and between participant and participant to generate data (Kitzinger, 2006). The group nature of focus groups allows participants to divulge information and emotions that questionnaires or interviews do not (Krueger, 1994).

A focus group typically involves 6-12 participants who share a common interest. Qualitative methodologists Morgan and Krueger both describe the use of "mini-focus groups" with as few as 3 participants if subjects have expertise or specialized knowledge in a given field (Morgan, 1997 & Krueger, 1994). Krueger suggests that focus groups size should be governed by two factors: "it must be small enough for everyone to have opportunity to share insights and yet large enough to provide diversity of perceptions" (Krueger, 1994, p.17). When group size is less than 6 it can allow for more detailed interaction amongst focus group participants enabling attitudes, beliefs and perceptions to develop further (Krueger, 1994). Multiple focus groups are used to ensure trends and themes are present across different groups and to ensure that dominant focus group participants are not solely defining a theme. Focus groups studies typically require 3-6

distinct focus groups before data saturation is achieved (Morgan, 1997). The intent of focus groups is to explore participant perceptions and beliefs and not to reach a consensus (Krueger, 1994).

The strengths of focus groups are generated through group environment and interpersonal interactions. Communication amongst subjects plays an imperative role, helping participants form opinions and build upon ideas expressed by others (Krueger, 1994). Focus groups promote group interaction, which explores respondent attitude, encourages deeper exploration of ones own ideas to help identify groups norms and encourages open conversation about specific topics (Kitzinger, 2006). The researcher serves as a moderator and objectively probes responses to encourage deeper discussion amongst participants. Group environments promote participant relaxation and removes inhibitions (Krueger, 1994). Kitzinger (2006) summarizes advantages of focus groups as: it potentially includes individuals who cannot read or write, it encourages participation for subjects that are hesitant to be interviewed alone, and promotes participation of subjects who believe they have nothing to say (Kitzinger, 2006). Additionally, focus groups are relatively cost-effective and allow for more rapid collection of results.

Summary

DD and ASD are chronic conditions that affect an individual's ability to interact with their surroundings. These impairments can include communication, behaviors, social skills and ability for self-care. Clinicians such as BTs and SLPs address communication and behavioral impairments using AAC systems. PECS is one form of AAC commonly implemented to improve functional communication while minimizing behaviors. PECS

relies on principles of ABA and has substantial evidence supporting its efficacy in children with DD and ASD. Clinicians often use the mediator model to involve parents in behavioral and communication interventions. In Ontario, the mediator model is a common method of PECS service delivery. BTs and SLPs often train parents by giving recommendations on initial assessment, implementation and evaluation of PECS with their child. Many studies have demonstrated that parents can be effectively trained to implement behavioral and communication interventions. These studies have shown that parental involvement improves child outcomes. Many factors have been demonstrated as bridges and barriers to parental adherence of interventions.

Despite immense research on the mediator model, parent training, and factors influencing parental adherence to treatment recommendations there is a paucity of literature investigating factors that contribute to parental adherence towards implementing PECS in the home environment (Angelo et al., 2005; Durrand, 1999).

Purpose

Given the potential benefits of the mediator model, this study sought to investigate factors that influence parental adherence to PECS implementation in the home environment. There is a need for further study into the factors that help and hinder parental implementation of PECS in the home setting. This study used qualitative methods to investigate the factors that contribute to parental adherence.

Research Questions

This study was designed to answer the following research questions:

1. What are clinician's expectations of parents implementing PECS within the mediator model of service delivery and what do they think parent's expectations are of them?
2. Do clinicians believe parents find it easy and/or difficult to adhere to the clinician's recommendations regarding the implementation of PECS with their child in their home environment?
3. Specifically, what factors contribute to parental adherence or non-adherence to clinician recommendations on the use of PECS with their child?

Method

Recruitment:

Ethics approval was granted through the Brock University Social Science Research Ethics Board (REB). Initial approval was granted in December 2010 with subsequent modifications to approve broader research scope and recruitment.

All participants for this study were recruited from the Greater Toronto Area (GTA) between January 2011 and June 2012. Recruitment utilized three major methods. A one page introductory flyer was posted on the Autism Ontario website. Additionally, clinicians were recruited through Autism service organizations and the College of Audiologists and Speech Language Pathologists of Ontario (CASLPO). GTA Autism service organization directors were contacted and provided detailed information on this study. Several organizations were asked to disseminate information. Once clinicians expressed interest, participants were actively recruited by telephone or e-mail. The

purpose of the study and inclusion criteria was further discussed by telephone with interested candidates. All candidates were notified that participation was strictly voluntary and that they had the right to withdraw at any point in time. Additionally, it was stressed that all information would be kept confidential. If interested, the clinicians were provided with the letter of invitation, which described the background and rationale for the study and an informed consent form (Appendix A,B). Clinician concerns, questions and review of the informed consent were thoroughly discussed via telephone prior to the focus groups.

After study participation, a modified snowball technique was used to further increase study interest and recruitment. Study participants were asked to identify one or more potential eligible participant who may be interested in the study. Snowball sampling is well documented in the literature as a validated qualitative sampling strategy (Johnson & Christensen, 2008; McMillan & Schumacher, 2010). This technique allowed the research team to contact participants that were hidden or not otherwise accessible by earlier techniques.

This study's recruitment strategy was used to maximize the scope of recruitment and enroll as many interested and eligible participants as possible. The recruitment strategy was iterative and adapted based on clinician interest and recruitment successfulness. When it was clear that passive recruitment through flyers on websites including Autism Ontario and CASLPO was not effective a more active approach was undertaken. This approach involved more active solicitation as described above. Prior to changing the recruitment technique, REB approval from Brock University was sought and granted.

Participants:

The initial study protocol planned for the recruitment of 2 focus groups with a total participant number of 10-16. Focus group size and total subject number was then modified to accommodate for clinician interest while still including a large enough sample to achieve theme saturation. While not truly a purposive sampling technique, this study stopped accruing after analysis confirmed that the final focus group was not contributing to any novel theme development and theme saturation was achieved. Purposive sampling is a validated nonrandom qualitative sampling technique in which the researcher selects specific individuals with particular qualities to best inform the research topic of interest. After a sufficient amount of subjects have been selected, additional participants are not further required (Johnson & Christensen, 2008; McMillan & Schumacher, 2010). Following this purposive technique, this study stopped selecting further subjects once theme saturation emerged.

Ultimately this study recruited 8 participants. Three focus groups were held, each with two to three participants. The inclusion criteria for clinicians was:

1. Practicing Speech Language Pathologist or Behavior Therapist
2. Recommendations provided to at least 5 separate families on the implementation of PECS in the home environment
3. Ability to receptively and expressively communicate in English without an interpreter.

Focus Groups

Focus groups were held in locations convenient for study participants. All studies were held in a conference room or boardroom which were small, private and free of distractions. Discussions occurred around a circular table to build rapport and promote in-depth discussion. Present at each focus group was a study moderator and the study principal investigator (PI). The study moderator sat at the round table and was involved in all questioning. The PI was not at the table and served as recorder documenting non-verbal communication and ensuring proper focus group technique and questioning. This was used to increase trustworthiness and ensure proper transcription and interpretation of the data.

Each focus group lasted between one and two hours. Focus groups contained three components: an introduction with review of informed consent, a demographic questionnaire (Appendix C) and a focus group discussion. After informed consent was obtained, participants were provided a fifty-dollar honorarium and were informed that they could withdraw from the study at any time.

Audiotape or digital recording was initiated at the beginning of the focus group discussion component and was remained on for the entirety of the meeting. Focus groups were conducted using a semi-structured format that was adapted based on group discussion. A flexible script using open-ended questions was used to guide discussion (Appendix D). Script questions were based on a technique described by Krueger (1994, p. 54-55). As the focus group progressed, question focus narrowed and centered on questions specific to parental adherence. Opening questions were used to build rapport and collect demographic data. Introductory and transition questions began discussion centered on parental adherence. The key questions focused on deeper exploration of participant beliefs and attitudes towards factors that help or hinder parental adherence to the recommendations on the implementation of PECS (Krueger, 1994). The group moderator did not participate in the discussion, but asked probing questions to further explore phenomena. After each discussion point, participants were invited to state whether they agreed or disagreed with the discussion. If divergent ideas were expressed, participants were invited to expand further.

Data Organization and Transcription

After focus group completion, audio recordings were stored and accessed solely at the PI's secured Toronto office. The first focus group used audiotape recording that was securely stored. The subsequent two focus groups used digital recording and were stored on a password-protected computer. Verbatim transcription of audio recordings occurred within one week of each focus groups completion. This verbatim process transformed audio data into typed text using the exact word for word transcription. The transcription of three recordings took between 2-4 hours to complete. The written format of this

study's' transcriptions were based on suggestions by Cresswell (2008) utilizing large margin spaces, bolded headings and typed in explanations (i.e. long silence) to facilitate the visual analysis process (McMillan & Schumacher, 2010). After ensuring adequate back up, all audio recordings were destroyed within 1 week of transcription of each recording.

Data Coding and Analysis

Qualitative research involves iterative inductive analysis in which researchers collect and categorize data to develop themes and relationships that represent phenomena. There is no standard approach to qualitative analysis. Researchers develop eclectic techniques that best summarize their data. Often times, data analysis techniques change throughout the duration of the research study (Mcmillan & Schumacher, 2010).

This study employed a conventional data analysis technique. The researcher reviewed the transcript three times. Throughout the review, the researcher engaged in "memoing", writing down reflective notes on a separate pad of paper to get a sense of the whole dataset and to initiate the development of codes (Johnson & Christensen, 2008, p. 532). Coding began once data segments were separated within the transcription. *Segments* are data elements that vary in size and contain a single piece of information that can be understood by themselves (Johnson & Chistensen, 2008; McMillan & Schumacher, 2010). The separated segments were utilized to form initial inductive *codes,* a name or phrase used to describe the meaning of a segment that are generated by a direct examination of the data (Johnson & Christensen, 2008). Some codes consisted of the participant words ("in vivo codes"), whereas other codes were synthesized from the

discussion (McMillan & Schumacher, 2010, p. 371). Codes were tracked with color coded text as well as an alphabetic scheme. A legend was created to track the meaning of each color and alphabetic schema. A list was created after coding which summarized the coding scheme.

Codes were then identified as major, important or minor. The major codes were defined as codes that occurred often and/or in-depth throughout the transcript. The important codes were defined as codes that were mentioned a couple times and discussed throughout the transcript. The minor codes were defined as codes that were mentioned rarely and briefly within each transcription. After identifying major, important and minor codes, the process of "enumeration" took place (quantifying data). The researcher quantified the frequency of each code within the transcription and tallied it at the bottom. Code frequencies helped the researcher recognize the importance of certain codes (Johnson & Christenson, 2008). Following enumeration, the transcript was reviewed in its entirety to confirm that these codes met the aforementioned definition. This process was repeated for each focus group. Coding schemes were unique for each focus group.

Once each transcript was coded and reviewed, a master table was created identifying all codes used in the study. This master table served as the initial template for theme identification. Themes are defined as entities of codes grouped together (McMillan & Schumacher, 2010). Criterion for theme identification in this study was defined as either a major code within one focus group or an important or minor codes across 2 or more focus groups. Following the definition of a theme, an unmarked version of each transcript was reviewed and discussion points were highlighted as per thematic category. This process was repeated for each transcription. Constant comparison analysis was used

to modify themes and ensure all major discussions were identified across all 3 focus groups. Patterns were later grouped and used to identify commonalities seen between themes. McMillan and Schumacher (2010) defined a pattern as " complex links among various aspects of people's situations, mental processes, beliefs and actions" (McMillan & Schumacher, 2010, p. 378). Constant comparison analysis was used comparing codes, themes and patterns to ensure the simplest, most logical segmentation.

Constant comparison analysis, developed by Glaser and Strauss (Glaser, 1965; Strauss, 1987; Strauss & Corbin, 1998) is a "recursive process in which the researcher continuously searches for supporting and conflicting evidence regarding the themes" (McMillan & Schumacher, 2010, p. 377). Through constant comparison analysis, the researcher is assessing theme saturation across all groups. The benefit of constant comparison analysis is that one is able to assess if the emergent themes in one focus group also occurred across the other focus groups (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). Constant comparison analysis allows for the identification and representation of both convergent and divergent ideas. Constant comparison provides a robust description and allows for presentation of multiple perspectives.

Data Presentation

Themes were presented using a narrative approach. Support for themes was generated in the form of participant quotations. Quotations attempted to provide equal representation of each participant.

Trustworthiness analysis

Qualitative research suggests assessing the trustworthiness of data through evaluatation of credibility, fittingness, auditability and confirmability. This process increases study rigor and validity (Guba & Lincoln, 1981). This study incorporated techniques to ensure trustworthniness using the above princples. These techniques included safegaurds against bias, structural corroboration, and a degree of external auditability. To prevent against bias and ensure structural consistency during the focus groups, open-ended and non- leading questions were asked. Furthermore, a non-participating observer attended all three focus groups and provided feedback to the moderator regarding maintaining objectivity while building rapport with the participants to prevent bias. This non-participating observer reviewed transcripts to verify that moderator opinions and bias was not inserted into the data. Guba and Lincoln (1981) describe structural corroboration as "the process of gathering data or information and using it to establish links that eventually create a whole that is supported by the bits of evidence that constitute it" (Guba & Lincoln, 1981, p. 105). To ensure credibility through structural corroboration, this study involved a member-checking technique. Subjects were asked to take part in a member-checking process to verify that the verbatim transcriptions accurately represented what was discussed in the focus group that he/she participated in. A participant acted as a member-checker by reading through an anonymized transcription of the focus group. This member-checker agreed that the transcription accurately represented the focus groups ideas and statements and that it was truthful to the essence of the discussion. Most participants were invited to serve as member checkers, but the

majority declined as they believed that the discussions were correctly transcribed from the outset.

Guba and Lincoln (1981) discuss fittingness as the ability to maintain the context of participant statements and not draw generalizations. Member checking was used to ensure that statements were not generalized or taken out of context. This study did not specifically address generalizability. As previously mentioned, this study was designed to be hypothesis-generating and to explore phenomena in depth. As such, the results represent the 8 focus group participants' opinions, but do not necessarily represent the opinions of all clinicians.

Guba and Lincoln (1981) discussed the role and benefit of external auditors, who review the study without the potential bias of the research team and develop a "level of agreement by looking at one's background, and perspective" (Guba & Lincoln, 1981, p. 123). An auditing approach was used to evaluate and ensure consistency (auditability) of the focus group transcriptions, the inductive coding process, and the constant comparison analysis of emergent themes. An external doctoral-level auditor, with considerable training and experience in qualitative analysis, reviewed this study's iterative coding approach to ensure sound methodology. This auditor was in strong agreement with the coding of the transcripts of each focus group, and the amalgamation of codes across the three patterns. Further, the auditor offered only minor refinements to the wording in the final thematic analysis that were incorporated (i.e. the word X instead of Y).

Results

Demographics

Recruitment for this study took place in the Greater Toronto Area (GTA). In total eight clinicians participated in three mini-focus groups. Demographic information is provided (Table 1). Participants included one man and seven women. Ages ranged from 26-52 (mean= 33.125). There were six BTs and two SLPs. Six participants worked for publicly funded institutions and two worked for private institutions. Each participant had experience providing parental recommendations on PECS implementation in the home environment. Participant experience ranged from 2 to 26 years (mean = 10.69). Seven participants spoke English as a first language, the eighth participant spoke and understood English fluently, though it was not her native tongue.

Table 1

Participant Demographic Information

Participant	Focus Group #	Age	Sex	Type of Clinician	Years of experience	Role	Public or Private	English as first language
1	2	32	M	BT	9	Coordinator of behavioral management services	Public	Yes
2	2	32	F	BT	10	Coordinator of ABA program	Public	Yes
3	2	30	F	BT	10	Clinical coordinator of ABA services	Public	Yes
4	3	30	F	BT	10	Behavioral Consultant	Public	No
5	3	26	F	BT	2	Behavior Therapist	Public	Yes
6	3	31	F	BT	12	Behavior Therapist	Public	Yes
7	1	52	F	SLP	26	Speech Language Pathologist	Private	Yes
8	1	32	F	SLP	6.5	Speech Language Pathologist	Private	Yes

Note. M=male, F=female, BT=Behavior Therapist, SLP= Speech and Language Pathologist.

To verify the relevance of the participant's experience to the group, each clinician was asked to describe how long they have been a clinician and their job description. Experience with parental recommendations included:

"I have taught PECS to various mediators (i.e. parents, caregivers, teachers, IBI instructors) to develop communicative language and/ or augment the development of

verbal behaviors such manding (i.e. requesting) and tacting (i.e. match-to-sample; labeling). I have implemented PECS during Functional Communication Training (FCT) when problem behaviour is of concern. More specifically, I have used PECS to communicate access to attention, tangibles, and/ or escape, as a function-based treatment/ alternative to problem behavior".

"Currently I'm working as [a] behavior consultant which involves parent training, mediator training and basically working with the mediators to teach them how to work with the kids".

This thesis was designed to address 3 related research questions. The codes generated by constant comparison analysis were used to answer all 3 research questions and results are representative of all 3 focus groups. The subsequent sections will address each research question individually.

Research Question #1: What are clinician's expectations of parents implementing PECS within the mediator model of service delivery and what do they think parent's expectations are of them?

Constant comparison analysis was used to analyze codes relating to clinician and parental expectations. Clinicians had diverse expectations of parents implementing PECS within the mediator model. Many clinicians reported that their ultimate goal was to achieve 100% parental adherence. For example, participant 1 stated, "our expectations when we go in with recommendations is to follow through with those recommendations or to attempt to." This participant continued to say:

> "I think every clinicians goals end is 100% we all have that in the back of our minds, we can be as diplomatic as much as we want but I think we all want 100% adherence when we have put recommendations in that's our goal".

Although the goal is perfect follow through, many participants discussed parental misunderstanding of recommendations. Some participants expected that parents would fail regardless of intensive training. At times, clinicians believed that any form of parent training would not lead to results. Participant 7 reports past failures: "So even though you are saying you need to know phase 1, you need to wait to identify this or that, change patterns in the home…[even though] they walk out knowing that, I know that they are going to be practicing error all week." Although clinicians discussed past failures, many clinicians discussed strategies to improve parental adherence to PECS recommendations (see next sections of discussion).

Further, clinicians have variable expectations based on past experiences with specific parents. Participant 8 stated that:

> "We tried this at home and it worked really well some even bring back the homework that I give them. We will give those parents more to do… what you expect of the parents [is] based on the homework you give them."

Although clinicians had expectations of parents, it was clear that parents had expectations of clinicians and the mediator model. On initial assessment, clinicians found that parents had diverse expectations on PECS delivery and the concept of mediator training. In some instances parents expected the consulting clinician to be the sole provider of PECS implementation. On the other hand, some parents wanted complete independence and were "eager" for the clinician to leave the home setting. Participant 3

best summarized the divergent parent expectations:

> "We always have that sort of spectrum when it comes to the types of parents and sort of their perspective of what service is going to look like. And I think the extreme ends of the spectrum are parents that are eager to have you come in, and are looking forward to the day that you are gone so that they have the skills and can work with their child. Then on the other end of the spectrum you may have the parents that want you to fix the problem and you to be in they're working with their child and are reluctant to give you up. And then of course you have your parents in between that give you a bit of both, so I think sometimes so we have those extreme cases you're going to fix all the problems versus I [clinician] need[s] to be the one responsible for maintaining low behavior rates or skills acquisition moving forward the sooner you can come in and show me what to do the sooner I can say bye to you".

Further, many clinicians reported that parents had unrealistic expectations of PECS implementation using the mediator model. Parents often wanted "quick fixes" for their child. Participant 5 stated that:

> "Parents think that they can come bring their children and they are going to come back fixed and that there is not necessarily the expectation that their going to have to also do things in a different environment at home".

Similarly, participant 1 discussed that parents have unrealistic expectations of the mediator model and PECS implementation:

> "Sometimes they come up with some large goals and some parents come in with specific goals that they wants us to work on. Sometimes through the lines of a

clinicians, some of their goals seem unrealistic unfortunately and sometimes it makes it difficult for some clinicians".

It is clear that both parents and clinicians have diverse expectations on PECS implementation using the mediator model of service delivery. In many instances, expectations are shaped by past experiences.

Research Question # 2: Do clinicians believe parents find it easy and/or difficult to adhere to the clinician's recommendations regarding the implementation of PECS with their child in their home environment?

Constant comparison analysis was used to analyze codes relating to parental ability to adhere to PECS recommendations. Although the majority of codes discussed adherence, the codes analyzed for this section were solely related to ease of PECS implementation. Most clinicians believed that providing PECS recommendations to parents was a complex process and that it was difficult for parents to adhere to treatment recommendations. Participants discussed that the underlying behavioral techniques used in PECS including error corrections, use of back-prompters, and reinforcement were not intuitive to parents. Participant 2 best summarized many participant views on the complexity of PECS delivery:

"The component of the whole error corrections procedure when it comes to PECS phases… is quite a difficult process to learn and when to implement certain error correction versus other error correction depending on the error made and identifying what that is and then going through those steps that they need to do… I think just the intricacies of it because it is so specific"

Participant 5 confirmed this statement and discusses how this complexity

influences adherence. She stated, "I think a barrier for a lot of parents would be that its not necessarily, especially in the early stages … an easy system to start picking up." Participant 1 discussed that parents often don't understand the need for or have access to back-prompters, which are necessary for errorless teaching of PECS. This participant said:

> "Parents struggle with the whole idea of a back-prompter. In some situations parents don't have the back-prompter to help teach the different stages so that kind of holds or acts as a barrier sometimes in teaching PECS and then they say I can't do this".

Additionally, participants suggested that parents did not understand that PECS is a form of "communication/voice". Participants discussed that parents did not understand that PECS should be used in a variety of settings and not only on a parent's contingency. As such, it was difficult for parents to adhere to PECS recommendations. Some parents blocked exchanges and used PECS incorrectly to meet their parental needs at the detriment of their child's needs. Participant 7 recalled a cynical response from a parent. While the participant inquired about the location of a PECS binder a parent stated, "well yah but we don't want him to ask right now, he can't interrupt".

Participant 5 further developed that parents not understanding PECS as a voice impacted parental adherence. This participant stated:

> "I think the main thing that's hardest for a lot of parents is to understand that it really is the same as a voice so blocking an exchange or not giving the child access to the book , I have to use the example it's essentially covering your child's mouth, right. Vocal children can repeat for something as much as they want or ask

> for something that they you don't have but they still have the opportunity to do that, but a lot of parents don't get that cause their like what's the point in letting my child ask for this when I know I cant give it to them".

As stated above, PECS implementation requires a step-wise approach. If parents do not understand the importance of proper PECS implementation, they potentially can proceed non-systematically through the steps, thus not adhering to treatment recommendations. Participant 6 summarized this:

> "I think it's also difficult for parents when they are teaching their kids how to use PECS to not move ahead too quickly…and like you know once their kid start showing some signs of understanding the exchange all of a sudden they have like 20 thousand pictures on their board and the expectation just grow so much. I think it's hard for parents to be patient to follow the steps".

These discussions indicate that clinicians believe that PECS is complex and recommendations are difficult to adhere to. Clinicians believe that parents often lack understanding of behavioral principles used in PECS and are inpatient with its stepwise approach. In the subsequent section, this report will discuss that clinicians believe that there are bridges to facilitate parental adherence to PECS recommendations and that some parents are able to adhere to recommendations despite PECS complexity.

Research Question # 3: Specifically, what factors contribute to parental adherence or non-adherence to clinician recommendations on the use of PECS with their child?

Themes

Focus group transcripts were analyzed using an inductive process involving idea segmentation (McMillan & Schumacher, 2010). Emerging codes were identified from the segmented ideas for each focus group. Overlapping codes were grouped. There were a total of 84 distinct codes identified with 27 in focus group 1, 27 in focus group 2, and 30 in focus group 3. Enumeration was conducted to quantify the frequency of code discussion in each focus group. For each focus group major, important and minor codes were identified based on the depth of discussion and enumeration. In focus group 1 there were four major codes, five important codes and eighteen minor codes. In focus group 2 there were nine of each major, important and minor codes. In focus group 3, there were five major codes, six important codes, and nineteen minor codes.

Once codes were identified for each focus group, constant comparison analysis was used to compare and contrast codes across all 3 focus groups. Again, overlapping codes were identified and grouped. In total 76 of the 84 (91%) codes were discussed in two or more focus groups. Using this recursive constant comparison technique, six high-level themes emerged (Table 2, 3).

These themes were:

(1) professional factors

(2) psychological (attitudes and motivations)

(3) knowledge mobilization

(4) service delivery and follow through

(5) social

(6) behavioral

Table 2

Thematic Definitions

Theme	**Definition**
Professional Factors	Any factor related to clinician education, advanced training or experience.
Psychological	Any factor related to cognitions, beliefs, values, expectations, attitudes or motivations.
Knowledge Mobilization	Any factor related to transfer of knowledge, transfer technique or understanding.
Service Delivery	Any factor related to a child's multi-professional treatment team, the availability of clinicians or the physical practice of using PECS.
Social	Any factor related to one's physical, cultural, and living environment.
Behavioral	Any factor relating to a child's actions and conduct.

Table 3a.

Thematic Analysis for Clinician Pattern

High Level Themes *Patterns:*	**Professional Factors**	**Psychological (Attitudes & Motivation)**	**Knowledge mobilization**	**Service delivery and follow through**	**Social**	**Behavioral**
Clinician	Training Level of Experience/ Skills Knowledge of clinical best practice Up to date with technology	Preconceived notions (lack of confidence in parent) Clinician expectations ("fear of failing") Clinician contact with reinforcement	Parental misunderstanding of PECS Parental initial education on PECS How to train/educate parents ("hands on component", "written instructions", "clear instructions", "modeling", "feedback" ,"irregular follow-up visits") Parent training in multiple environments Parent training and type/how of train/adaptable training technique (" how conducted" , "language I understand", "make sure feel confident" ,"parental empowerment", "practicing") Clinician antecedent approaches ("addressing potential challenges", "creating errors", "troubleshooting", "problem solving") Realistic recommendations ("recommendations that will fit") How clinician initially presents PECS Clinicians understanding of parents' different styles and being in their shoes/parent-led	Clinician time restraints Inter-professional conflicts Clinician open communication Addressing potential challenges "assessment of mediator skills"	Catering to the needs of parents Building rapport Adaptable to environment ("Feel heard", "Mindful clinician")	

Table 3b.

Thematic Analysis for Parent Pattern

High Level Themes *Patterns:*	**Professional Factors**	**Psychological (Attitudes & Motivation)**	**Knowledge mobilization**	**Service delivery and follow through**	**Social**	**Behavioral**
Parent		Parental expectations/Parents' unrealistic goals Preconceived notions of BT Parental motivation (willingness to learn/request feedback/"eager"/conflicting parental values") Parental "buy in" (who's idea to begin PECS/"empowerment") "Parental contact with reinforcement" (rewarding/ effectiveness of PECS) Clinician provided reinforcement	Parental access to material and parental empowerment Parental lack of knowledge PECS = voice Improper use of PECS implementation ("loss of opportunities", "moving ahead")	Complexity of PECS ("error correction", "back prompter") "Extra support"	"Other parent support groups" Parental perceived stigma of PECS Language barrier Spousal disagreement over intervention Parental education "Family Dynamics" (living/work situation, # of kids, # of parents involved, time constraints martial status, # of parents, parental role/availability "potential diagnosis", "geographical area", "access to services", "siblings as communicative partners", role of divorce and living in two households, "siblings behavior")	

Table 3c.

Thematic Analysis for Child Pattern

High Level Themes *Patterns:*	**Professional Factors**	**Psychological (Attitudes & Motivation)**	**Knowledge mobilization**	**Service delivery and follow through**	**Social**	**Behavioral**
Child		Childs motivation/ satiation	Childs current knowledge of PECS/ skill level of learning Rapid PECS acquisition	Incongruent recommendations other/multiple professionals Child involvement in other services Consistency/involvement of environments/other professionals		Reinforcement # Challenging behaviors/ frequency of behavior(s) Response effort/practice

All themes were discussed in at least two focus groups. The third focus group had reached theme saturation. There were no new major or important codes discussed in the third focus group. The only two codes that were solely mentioned in focus group three were minor and formed fragments of other discussed codes. Further focus groups were not recruited, given theme saturation.

Constant comparison analysis demonstrated commonalities between the six themes that generated super-categories termed patterns (McMillan & Schumacher, 2010). The patterns were clinician, parent, and child which encompassed the aforementioned themes. To avoid confusion, professional factors was a defined theme while clinician factors was a pattern which encompassed professional factors. Four themes were contained in all three patterns. Professional factors were only relevant to the clinician pattern whereas the behavioral theme was only relevant to the child pattern. Detailed themes will be discussed as they pertain to the clinician, parent and child. This presentation method was chosen because themes within each pattern (i.e. clinician, parent, child) were more interrelated than themes across patterns.

Clinician factors that influence parental adherence to the implementation of PECS

Five of the six high-level themes were identified as clinician factors that help and/or hinder parental adherence to the implementation of PECS. Within the clinician pattern, professional, psychological, knowledge mobilization, service delivery, and social themes were present. The theme that was not represented as a clinician factor was behavioral. The majority of themes were present in all three focus groups and were common across BTs and SLPs. Although initially some codes were thought to fit the

behavior theme, with further analysis it was clear that they better fit into psychological and knowledge mobilization themes.

Professional factors

Professional factors influencing parental adherence fell into three classes: training, experience, and knowledge of current research and clinical best practice. Participant 7 discussed her training and knowledge of best practices within her field and their positive influence on parental adherence:

> "Trained as a speech pathologist, and looking at the literature on evidence-based practice…[I] know the importance for intensity of intervention once a week…[I] leave a lot of homework for parents to do and give them a lot of recommendations for home".

Participant 2 reported the importance of clinical experience and skills in promoting adherence to PECS recommendations:

> "If the clinician is going in with kind of a bag of tricks that they know in the past solve that issue, I think that helps a little bit but the level of experience of someone walking in plays a huge factor. If you're fairly new and you have a little very little experience teaching it then you have very little to draw from, but the more you can draw from the better, more creative anyway…having different success stories or not…it all depends on the skills of the clinicians".

Similarly, participant 3 believes that her clinical experience allows her to adapt to different situations, increase parental understanding and promote adherence:

> "I think although every family situation is going to be unique and different I think there may be some commonalities across those families that have poor adherence

> … those could act as our list of red flags as a clinician going in that how can I, you know figure out if this component, this red flag that I have already identified with past parents is going to be an issue with this present family".

Participant 3 also believes that it is important to combine her knowledge and skills with current best practice and modern technology in encouraging adherence:

> "I think being up with technology is huge…A modality that has been trained, tested and true and tried…knowing the pros and cons of all of that and using the professions that are at your disposal to draw from such as an SLP, is really important, so you know I mean its just knowledge on the clinicians part to understand pros and cons of certain things and why we recommend a certain modality".

Participant 2 discusses the importance of an up-to date approach, which promotes parent adherence. She discusses

> "Focus on [an] evidence based approach in training and teaching PECS. I think in the field in general you have individuals who are up to date …on how to teach in general, but you know using some evidence based approaches in teaching PECS… a lot of research right now is on behavioral skills training approach and modeling rehearsing and actually training the mediators implementation of skills is shown to be effective and other approaches general case strategy".

Psychological (attitudes and motivation)

Clinicians identify the impact of their pre-conceived notions, clinical expectations and need for contact reinforcement.

The stated goal of many clinicians was to gain one hundred percent adherence. Participant 1 stated:

> "I think every clinicians goals end is 100% we all have that in the back of our minds, we can be as diplomatic as much as we want but I think we all want 100% adherence when we have when we put recommendations in that's our goal".

Although the goal is perfect adherence, many participants expressed a fear of failure, parental misunderstanding, and non-adherence. As such, their parental recommendations were affected which potentially served as barriers to parental treatment adherence. Participant 2 repeatedly mentioned a "fear of failing" and a "fear of gravitating towards something" new. This participant wanted to be more creative, but was unsure if she could do it "safely… professionally and responsibly". Although this participant wanted to introduce best current practice and technology, she was unable to and referred to "falling back on the same old same old". Similarly, participant 7 reports past failures and their impact on parental adherence:

> "So even though you are saying you need to know phase 1, you need to wait to identify this or that, change patterns in the home…[even though] they walk out knowing that, I know that they are going to be practicing error all week".

This participant expressed a lack of confidence in the parent as a mediator. Participants believed that this pre-conceived notion can potentially influence future recommendations which could further hinder parental adherence.

Participant 1 discussed the negative effect of a lack of contact with reinforcement for himself. Past failures with adherence discouraged this clinician and served as a further barrier to parental adherence:

> "Its similar to parents implementation of strategies contacting reinforcement as clinicians we also want to have contact with reinforcement so we want to see that progress as well, so the lack of adherence means that we are not contacting reinforcement of them completing the program and seeing success, so it definitely does discourage the clinician when they don't see the adherence or the program succeeding".

Contrary to these discussions, participant 8 discussed past successful parental adherence to provided recommendations and the positive impact it had on future recommendations. This motivated the clinician to work more to help the parent and further adherence.

> "We tried this at home and it worked really well some even bring back the homework that I give them. We will give those parents more to do, extra work on my part too right? To be able to provide all … what you expect of the parents [is]based on the homework you give them. That's what they are here for".

Knowledge mobilization

The most discussed clinician theme in all three focus groups was knowledge mobilization. In fact, there were one to two major knowledge mobilization codes in each focus group. Knowledge mobilization can further be broken down into training techniques and training skills. Although techniques and skills have overlapping definitions, the skills were ubiquitous throughout the training techniques. Common techniques discussed in all focus groups included: (1) initial education on PECS including "power point presentations" and "handouts", (2)"modeling", (3) "hands on

coaching", (4) "advanced skills training", (5) multiple environment training (participant 7) and (6) "troubleshooting techniques"(participant 7).

Participant 2 identified parental misunderstanding as a barrier to parental adherence on PECS recommendations. Despite training, one parent continued to confuse other visual aids as PECS and was non-adherent with recommendations. Following this interaction, this clinician spends considerable time on educating parents on what PECS is to facilitate adherence. Participant 8 discussed the role of technology and the concise description of PECS phases in training parents as mediators and promoting adherence: "There was one power point presentation that was so well organized each slide had like 3 points on it, each phase and had visuals and it was so clearly organized". Participant 7 always "reeducates people about what communication is". Participant 4 reported "orientations for parents" and description of PECS phases at intake.

Participant 1 discussed the role of modeling to train parents in proper implementation of PECS:

> "That practicing so they get to see how you do it, and also you're there to prompt, provide feedback and model for them so that was something that a lot of parents find useful. The feedback I got from one family that was just really helpful for me [was] to see how you did it and then seeing how you're there to help me with the implementation".

Participant 7 bridges the concepts of modeling and hands on coaching. She stated, "I get them to watch and then we say okay next you're going to take over so you're going to sit here and do the next exchange". Participant 3 and 8 confirmed the need for a "hands on component" when training parents as mediators. They discussed that not including a

hands on practice component to training is a barrier to parental understanding and future adherence to PECS recommendations.

Advanced skills training were identified as an important technique to facilitate parental adherence. Participant 2 discusses her approach to skill development by:

> "Breaking it down and creating errors maybe that you did or that didn't happen during the training but creating some complexity and seeing if the parents can problem solve their ways through it and giving them feedback on that and not only corrective feedback but an opportunity to reinforce those skills that your learning."

Following parental training, it is important to ensure understanding and comfort of the parent. Participant 2 mentions:

> "Not just saying good job check for the clinicians I did that I saw it I'm moving on, but really ensuring that they understand that they are comfortable in being able to read the situation as a clinician and reading the parents behavior and not just taking their verbal behavior as proof that they can do it".

Clinician skills, included "assessing mediator skills"(participant 1; 2; 3), technique adaptability, presentation of PECS package, "one on one direct support" (participant 4 & 5), involving both parents, behavioral skills training such as "written instructions"(participant 1;2;7), "modeling" (participant 2), "role-play" and "feedback", "ensuring understanding", "open communication", "language that is understood" (participant 2) "parental empowerment" (participant 3) and "videotaping" (participant 4 & 5).

Clinicians discussed the importance of baseline parental assessments to examine

baseline PECS knowledge and mediator skills. Participant 2 stated:

> "For a family this is going to be new…based [on] their learning history and based on their experiences with PECS, or a team number of different therapists, knowing that information, so kind of doing that full assessment of the family first so you knowing what you are going into as a clinician you're setting the situation for an ideal and optimal situation where you will more likely to get adherence".

Participant 5 discussed the role of "written instructions" to help promote parental adherence:

> "I think even like clear written out instructions or just reminders for the parents that a quick reference helps more in an environment like that or when there are multiple people in an environment you know if there are other family members involved in the household that maybe have not actually been trained on how to use it".

It is important that instructions are clear to ensure parents adhere properly to provided recommendations. If one is not clear about PECS recommendations parents might implement PECS incorrectly. For example, participant 7 discussed how one parent "Called me one Saturday night and just said listen I have driven out, I have gone to McDonalds ten times today when can I stop? And it's like…you know obviously I didn't communicate enough that it [reinforcement] needs to be really immediate".

Participant 4 further develops the technique of written instructions by including "adherence checklists" to allow parents "to collect data on themselves" to promote adherence.

Clinician adaptability involves preventing potential barriers to parental adherence early by providing simple and easily understood information to promote parental follow through:

> "I think there has to be something in it for them right you have to make the goal salient to them, for them to actually want to follow through…just simplicity or singling out one thing at a time that makes it easier for a parent to comply with and not overwhelm them"(participant 5).

Clinician adaptability also involves recognizing that "all parents have different styles" (participant 8). Participant 1 identifies different training styles for different parents to bridge adherence:

> "Different types of training are involved be it the SLP, BT or behavior consultant whoever is training the parents on PECS how are they training them. Here is your program, follow the program versus more of an intensive hands on approach or a behavior skills training approach so its how you train the parents and ensuring that when you leave your session with the parents they feel very confident in being able to implement the strategies".

Participant 3 builds upon the need for flexible and adaptable training techniques to promote parental adherence:

> "Ensuring that you have trained the parent adequately in order to have good adherence and that might mean determining what is the best type of training to provide a parent… assessing preference based teaching for a parent; is it going to be more of didactic model that is appropriate for the parent or are they going to need a lot of modeling, video, what's going be most beneficial for that

parent".

Participant 1 discusses the need for open communication and an adaptable approach. If one technique does not work, one needs to work with the parent to find a suitable replacement:

> "Our expectations when we go in with recommendations is to follow through with those recommendations or attempt to and if t doesn't work, for us to have open communication and try to see what's working and what's not working, and if its not working and to try to work with them".

Participant 3 confirmed the need for a flexible clinician. To help parental adherence, this participant discussed the need to indicate to parents that their "voice is being heard":

> "You know ensuring parent feedback drive where we take our next steps, and even indicating to parents too you know that we have tweaked this component due to feedback from other parents…it lets them know that their voice is being heard…"

The clinicians discussed the length of the PECS manual and how this could serve as a barrier to parental adherence. The complex material can be off putting to parents. Participant 3 discusses the complex "daunting" nature and different strategies to address this. She describes the reactions of some parents as:

> "Oh my goodness these are all the steps I have to complete before my child has a communication system, versus other parents looking at great now I know the next step, I know what we are working towards, this is good, this is helpful. It's not, do this stage and I don't know what to do next. So I think it depends on the parent,

> some parents might take it as oh my goodness you got to be kidding me 6 phases and this is what I have to do versus …thank you now I see the light and this is where we are heading".

Participant 1 confirms that it is a difficult decision whether to initially present to the parent the entire PECS manual or parts of phases. He continues to discuss his strategy in PECS segmentation:

> "Question, so when you [we] go to teach PECS, do we say PECS and present the entire [package]. PECS is really this big,…or we are going to teach this piece…here's a huge PECS package we're going to start on phase one, a small part of phase one but there's so many other phases. Its how as a consultant when we go in how do we present it, how do we teach it and really try to make response effort as quick and easy for them, and not as so daunting ".

Participant 1 continues to discuss the complexity of PECS and designing recommendations that "will fit parental needs and parental environment". Additionally, participant 2 and 8 confirmed the concept of going slow, giving "them a couple things to work on" and "making sure your recommendations are realistic".

Participant 3 discusses two techniques to facilitate PECS implementation throughout the family. She discusses the role of parental empowerment and the role of parents training other potential mediators. She stated, "we teach one mediator and that mediator turns around and teaches other people and that in itself might empower someone". In addition, she discusses the potential benefits of the clinician training both parents simultaneously to promote adherence and ensure consistency across both parents.

Participants discussed the need for multiple training sessions and regular clinician visits. Participant 6 reported irregular follow up schedules as a barrier to parental adherence; "If you're just going in once a month and…providing them recommendations and then not seeing them again I think its less likely that they are going to be able to follow through". Participant 7 further developed this concept and discussed increased sessions in different environments; "Of the children that I know, the ones that did the best are when we actually did the different settings ourselves… In session with us here and in session in the home".

Service delivery

Building on the theme of clinician knowledge mobilization, the theme of clinician service delivery aims to deliver the mobilization training techniques and skills in an efficient practical manner. Many discussed service delivery issues that negatively influenced parental adherence to recommendations. Clinicians discussed "time constraints", "geographic barriers"(participant 8), and "professional politics" as barriers.

Many clinicians discussed the finite nature of their time and how it was incongruent with the needs of families. Participant 7 stated:

> "Even though adherence may be better because they are now feeling confident that I can do this they are actually still not understanding… and you're letting them go because you cant just say wait I've got, we'll take the next three hours".

Participant 7 continued to discuss the barrier of training parents as mediators; "its that juggling of conversations that takes a lot of time" which she did not have available. Clinicians recognized the importance of detailed knowledge delivery, however refrained due to time constraints. Participant 8 stated "We tried this at home and it worked really

well some even some bring back the homework that I give them. We will give those parents more to do, extra work on my part too right?" This confirms that clinicians understand the importance of time and response effort in promoting adherence.

Clinicians discussed professional relationships and the inter-professional conflicts as barriers to parental adherence. Participant 4 stated that "the politics could definitely delay or impact" treatment adherence. She continued to state that:

> "There are some disagreements between professionals who work with the family. Lets say …consultants provide some strategies and the SLP who works, lets say through school, they have different ideas and sometimes they're not all you know in contact."

This participant reveled an anecdote of a recent clinical experience which attempted to promote clinician communication to improve parental buy in and adherence:

> "I had an experience where you know the parent even asked me to contact this other professional and just asking you know what they thought what was the reasoning behind it …very they felt like kind of attacked you know… I find there is some ego sometimes in the way… Its not about the child anymore".

Clinicians discussed the need to address "potential challenges" early to help parents "troubleshoot" when independently implementing PECS. By teaching parents to address barriers they can use the knowledge gained in training to deliver PECS successfully. During focus group 2, there was a detailed discussion between all three participants regarding addressing and troubleshooting potential challenges. Participant 3 discussed the importance of identifying barriers and delivering information in real world settings that utilizes parent skills training:

> "I agree with making it very real for the parent and you're right … they need to know how to deliver reinforcement for the child who correctly exchanges the PEC but what about those moments when behavior intervenes and how do we problem solve in those situations? So those examples and non-examples of what successful you know PEC exchange looks like, I think that's important that the parent doesn't always see… this is successfully how do you do it… so that when they are in the moment and its not going the way my clinician showed me what to do…asking we're going to be doing and what component of the package do [they] already see being a package".

Participant 2 confirmed the importance of identifying and addressing potential barriers to implementation. She stated "even if you do identify areas that may be a barrier or a concern for the family at least I think half the barrier is getting it out there". By identifying the barriers, clinicians agreed that they could minimize the barriers' effect and maximize parental adherence.

Social

Clinicians discussed the importance of adapting their service delivery to parent social environments. This technique was key to building rapport and designing recommendations that fit a family's' bio-psycho-social environment. Clinicians reported that being flexible and adaptable to various environments "optimize adherence". Participant 3 stated "as a clinician you need to be mindful … that might mean clinicians might need to tweak recommendations based on other components of the child's life biomedical components". Similarly, participant 2 reported "… being really sensitive to their other factors that are playing within that family or with that specific mediator".

Additionally, participant 4 addressed "you really need to get to know the mediator you're working with…seeing, brainstorm[ing] and problem solving what else you can do to make it more practical for them and make it work". Participant 3 best summarized these discussions:

> **"**I think catering to the needs of the parents and accommodating their unique situations I think that would optimize adherence and they feel as though they are being heard and you are very understanding of their home life, and setting events that may act as barriers".

Parent factors that influence parental adherence to the implementation of PECS

Four of the six high-level themes were identified as parental factors that help and/or hinder parental adherence to the implementation of PECS. Within the parent pattern, the themes that were identified were psychological, knowledge mobilization, service delivery, and social. The themes that were not represented in the parent pattern were professional factors, and behavioral factors. The majority of themes were present in all three focus groups and were common across BTs and SLPs.

Psychological (attitudes and motivation)

The psychological theme was the one that was most discussed as a parent factor contributing to parental adherence to PECS recommendations. In fact, there was a major code in each focus group dedicated to psychological factors including, parents expectations and parental motivation including "buy in, "parent contact reinforcement", and incongruent parental values.

On initial assessment clinicians found that parents have diverse expectations on PECS delivery and the concept of mediator training. In some instances parents expected

the consulting clinician to be the sole provider of PECS implementation. On the other hand, some parents wanted complete independence and were "eager" for the clinician to leave the home setting. Parents with realistic expectations were more likely to adhere to PECS recommendations. Some participants reported that parents' unrealistic goals of a quick fix for their child prevented adherence. Participant 5 stated that:

> "Parents think that they can come bring their children and they are going to come back fixed and that there is not necessarily the expectation that their going to have to also do things in a different environment at home".

Similarly, participant 1 discussed the need for parental realistic goals and talked about the negative impact of unrealistic goals on adherence:

> "Sometimes they come up with some large goals and some parents come in with specific goals that they wants us to work on sometimes through the lines of a clinicians some of their goal seems unrealistic unfortunately and sometimes it makes it difficult for some clinicians".

On the other hand, some parents have zero expectations from behavioral clinicians. Participant 6 discussed a parent who did not adhere to treatment recommendations because of their preconceived notions of behavioral therapy:

> "Working within the interdisciplinary team and everyone knows that I am connected to psychiatrist who prescribes medication and so I think that puts a different spin on things a little bit cause they may value behavior therapy a little bit less because there just like when is the psychiatrist going to do his job".

Participant 3 best summarized the divergent parent expectations and commented on the effect on adherence and skill acquisition:

> "We always have that sort of spectrum when it comes to the types of parents and sort of their perspective of what service is going to look like. And I think the extreme ends of the spectrum are parents that are eager to have you come in, and are looking forward to the day that you are gone so that they have the skills and can work with their child. Then on the other end of the spectrum you may have the parents that want you to fix the problem and you to be in they're working with their child and is reluctant to give you up. And then of course you have your parents in between that give you a bit of both, so I think sometimes so we have those extreme cases you're going to fix all the problems versus I [clinician] need[s] to be the one responsible for maintaining low behavior rates or skills acquisition moving forward the sooner you can come in and show me what to do the sooner I can say bye to you".

Parental motivation is another parental psychological factor that clinicians identified as a bridge and barrier to PECS adherence. Similarly to expectations, there is a wide scope of parental motivation from motivated to disinterested. Participant 7 shared that parents that are "excited" and ask questions about "research and current practices" were motivated and most likely to adhere. Participant 4 discussed how "very eager [parents] want to learn and they want feedback and they ask for it and they really appreciate whatever supports we can give them". Participant 6 advanced this concept by saying "motivation …has a huge impact on how much they [parents] can handle and willingness to do it". This confirms that motivated parents are more likely to adhere. Participant 5 discussed an example of a motivated parent:

> "We just started an unavailable page for a client and that seems to have been the easiest step with this parent. They are really on board with this, obviously this child is requesting a ton at home for things … she was right on board to sign up as early as possible…she's actually adhering to everything I said to use on the procedure…".

Motivation can be generated by a number of factors including "buy in" and "parental contact with reinforcement". Multiple participants discussed that parents were most motivated when they were the ones to choose PECS as their child's communication device. Participant 2 shared:

> "I think again the buy in component of the family who came up with the idea or the modality of PECS… whose idea was it to start doing PECS in the first place. Was it the therapist ideas, was it parent driven, did an SLP suggest it?"

On the other hand, parents who did not buy into PECS were less likely to adhere to recommendations. Participant 1 discussed a parent who was more motivated by new modalities:

> "Mom is like you know what I don't, is want the visuals. Everyone is moving toward Augmentative devices, Proloquo2go that's the big thing right now" and because the clinicians brought it up or the SLP brought it up not the parent, the buy in is not there as much".

Furthermore, participants discussed that parents "sit on waiting lists for so long that they are going to take that service whether they really want it or not, whether its helpful or not …", which affects parental motivation and adherence.

Another factor relating to parental motivation was if parents make "contact with reinforcement". Parents were more likely to be motivated if they saw "progress", and improved child outcomes, decreased maladaptive behaviors (participant 4), and/or if the clinician was providing "genuine reinforcement and social praise" (participant 2 & 4). Participant 1 stated; " parents can contact reinforcement meaning … they start seeing progress so the minute they start seeing progress their practicing the behaviors get reinforced and they'll continue". Additionally, participant 6 stated " I also think when they see the effectiveness of it …and when they see their kid start communicating that's[what] motivates them to do it more .

On the other hand, motivation and adherence can be decreased by incongruent parental values. Participants discussed that some parents do not want to always follow through with recommendations because their child's request is inconsistent with their parenting abilities and ideas. For instance, participant 6 shared that it is;

> "Also really difficult for parents to always reinforce the kid for asking using PECS. Like they don't want to give them that many cookies, or they definitely don't want to take them to McDonalds every time they ask for McDonalds especially when it involves things like food".

Similarly, participant 2 discussed:

> "I really don't want to do that even though he asked. I want to reinforce the skill, but I don't want to give him continuous access to popcorn or candy or whatever he is asking for. How do you cope with that from a program standpoint and adherence and wanting to please maybe your clinician doing a good job but then

being a good parent and holding up to your own values and beliefs and all of that".

Clinicians believe that parental attitudes and motivations serve as both bridges and barriers to parental adherence to PECSs recommendations. Parental expectations and motivations are shaped by past experiences, and could be further impacted by contacting reinforcement.

Knowledge and mobilization

Participants suggested that parents require a requisite knowledge base to ensure proper adherence to PECS recommendations. Parents needed to understand that PECS is a form of "communication/voice", and they needed to understand how PECS implemented properly.

Participants recalled the importance of parent understanding that PECS is a form of communication that is their child's voice. PECS cannot only be used on parent contingencies. Many participants recalled examples of parental non-adherence relating to this parental misunderstanding. Some parents blocked exchanges and used PECS incorrectly to meet their parental needs at the detriment of their child's needs. Participant 7 recalled a cynical response from a parent. While the participant inquired about the location of a PECS binder a parent stated, "well yah but we don't want him to ask right now, he can't interrupt".

Participant 5 best summarized some parents' lack of understanding of PECS as a voice and how it negatively influenced parental adherence:

"I think the main thing that's hardest for a lot of parents is to understand that it really is the same as a voice so blocking an exchange or not giving the child

> access to the book, I have to use the example it's essentially covering your child's mouth right. Vocal children can repeat for something as much as they want or ask for something that they you don't have but they still have the opportunity to do that, but a lot of parents don't get that cause their like what's the point in letting my child ask for this when I know I cant give it to them".

Participants discussed the significance of proper PECS implementation by parents. As previously discussed in the clinician knowledge mobilization section, the clinician needed to stress the importance of proper PECS implementation. Participants discussed factors that both help and/or hinder parental adherence to PECS recommendations. Parents are more likely to adhere to recommendations when they are using their child's PECS binder in different environments. Participant 3 discussed "lost opportunities" when parents "forget to bring the binder into the community based environment". Participant 1 advanced this idea by suggesting that using different communication forms in different environments confused parents and children, promoting non-adherence:

> "The one thing that can really set their training back is at home they are using PECS but at school they are using another method, and he goes to grandmas and he doesn't use PECS there all of the sudden the child keeps going back and using a form of communication that doesn't involve PECS they go back to working with mom and dad and all of a sudden a lot of skills are not there as much".

As stated above, PECS implementation requires a step-wise approach. If parents do not understand the importance of proper PECS implementation, they potentially can proceed non-systematically through the steps, thus not adhering to treatment

recommendations. Participant 6 summarized this:

> "I think it's also difficult for parents when they are teaching their kids how to use PECS to not move ahead too quickly…and like you know once their kid start showing some signs of understanding the exchange all of a sudden they have like 20 thousand pictures on their board and the expectation just grow so much. I think it's hard for parents to be patient to follow the steps".

In addition to this, parental misunderstanding of the proper implementation of PECS is a hindrance to parental adherence. Participant 3 reported that:

> " I think this can hinder you know the use of PECS as well, if everything is always available to the child, then you have limited the opportunities to practice using that communication system, and so by limiting practice then we [parents] limit you know the available the ability for the child to acquire that skill and then it doesn't look like progress is being made".

Parental knowledge mobilization is aided by access to material preparations for PECS recommendations. Many participants discussed the importance of parental empowerment. If parents were able to update PECS binders to make them applicable to their child's motivation, they were more likely to adhere to parental recommendations.

Participant 3 best summarizes parental empowerment and its role on adherence:

> "I think something that sort of helps with adherence is some of the material preparation that can be something that a consultant can or clinician can be apart of maybe in the beginning stages to jump start you know the implementations of PECS. I think that's huge for a parent and I think that over time the parent might become a little bit more savy in taking pictures and creating their own picture

symbols, but I think initially the expectation of all of the material and stimuli that is involved in this communication package to place that also on the shoulders of the parent might be a bit much".

These participant discussions indicate the need to educate parents on the role of PECS and its proper implementation. When parents understand what PECS is, they are more likely to comply with the provided recommendations.

Service delivery

Many participants discussed the complex and intricate nature of PECS. They discussed the confusing nature of whole error correction and the requirement of a back prompter in early phases of PECS implementation. As discussed above in research question 2, many clinicians discussed this "complexity" as a parental barrier to adherence to recommendations.

Participant 5 discusses how this complexity serves as a barrier to adherence. She stated, "I think a barrier for a lot of parents would be that its not necessarily, especially in the early stages … an easy system to start picking up"

Another commonly discussed service delivery barrier to PECS recommendation adherence was access to a back prompter that was previously discussed in research question 2.

Conversely, participant 6 believed that extra support can serve as a bridge to help navigate PECS complexity and to serve as a back prompter to assist in early phase delivery:

"I think it would be fantastic to start with extra support and extra people to make their response effort less for parents… and then they sort of see the success of it and your able to build some sort of behavioral momentum".

These participants discussed that PECS complexity could serve as a barrier to parental adherence. Extra supports can help overcome this barrier and serve as a bridge.

Social

Various social, economic, educational, and cultural factors were identified by participants as helping and/or hindering to parental adherence on the recommendation to PECS. Participant 2 best summarized the various demographic factors discussed in focus groups:

> "Coming up with certain recommendations and taking into account living situations how many kids they have on or off the autism spectrum, work situations, demographics … geographical area, access to certain services, supports … children in the home, current living situation I think, a harmonious family unit versus someone who's in turmoil or transition**…**and even the mental health of parents or the mediator involved as well and taking that into consideration or potential diagnosis it could be an issue"

Other participants discussed the role of "divorce and living within 2 households". Participants also discussed involvement of siblings and how they could serve as communicative partner "so it's not always this adult facilitated communication system, …these children can use it with there brothers and sisters" (participant 3). Participant 6 discussed how siblings can be both bridges and barriers to promoting parental treatment adherence. She stated:

> "The other kid works as a good model especially if they are typically developing, like they get the idea of PECS… so that can sort of help but often times just having to deal with the other kid or the other kid not want or getting to spend the same type of time with mom and dad, or not having access to these things, or not understanding what's going on , or having to deal with their behaviors in the background or just extra work…"

Additionally, parental free time and the role of both parents were discussed as a promoter of parental adherence. Participant 5 stated, "I think time factor can be a big thing depending on what the family has as an occupation and how much free time they spend with the child".

Parental agreement on following PECS recommendations also impacted adherence.

Participant 2 stated: "yeah I think the consistency piece of it too, not even in different environments but even in the same environment if mom is doing something different than dad and siblings and I think it gets a little confusing".

One participant mentioned that parental high-level of education can serve as a barrier to the parental adherence to PECS recommendations. Participant 7 stated:

> "Sometimes my poorest adherence is highly educated people, people in the technology industry …they see themselves certainly as at least equal to you if not above you in some things… and they don't think they need us…"

Participants 6 and 7 both discussed language barriers as factors to parental adherence.

Participant 7 stated, "I think another aspect especially in this area that's really

important is the parents' understanding of communication. So if their if English is a second language or third language, this becomes really, really difficult". Participant 6 believed that "language barriers make it hard to explain recommendations".

Parental social environment also included their peer and clinical milieu. Participant 6 viewed "parental support groups" as a "big hindrance because we might be talking about PECS…[parents] might hear from a friend how cool Proloquo2go is … and then they want to start doing that instead".

Stigma was also identified as a social factor influencing parental adherence. Participants stated that parents were hesitant to use PECS even if they understood that it was evidence-based because they feared that the PECS binder would bring attention to their child. Participant 5 stated:

> "There's a lot of I know I have a number of parents have a lot of hesitation period at the start just because of the stigmatization at the start …just because of the PECS binder… and that it obviously singles the child out in most environment …which even though they may understand as the best method, would be hesitant to actually follow through with it".

There are many social factors that were identified that influence parental adherence. These are best summarized as demographic, social milieu, clinical milieu, and social stigma related to PECS.

Child factors that influence parental adherence to the implementation of PECS

Child factors were the least frequently discussed pattern. Child factors were discussed in every focus group but were only defined as a major code in one focus group.

Four of the six high-level themes were represented in this pattern. Within the child pattern, psychological, knowledge mobilization, service delivery, and behavioral. Just as professional factors were a major theme for clinicians, behavioral factors were the major theme for children. The themes that were not represented were professional factors and social. Child social factors overlapped with parental social factors and as such, were grouped within that theme.

Psychological (attitudes and motivation)

Only one child psychological factor was identified. Child motivation was discussed in two focus groups and served as a bridge to parental adherence. Participants discussed the need for highly preferred reinforcers to entice and maintain child motivation. Participant 2 believed that, "It's really important and we kind of gloss over it a lot of the time [to] reinforce your child make sure they get access to [the] reinforcer when they give you that PEC and it's all about you know contacting reinforcement from their stand point".

Knowledge and mobilization

Child baseline skill level influenced knowledge mobilization and facilitated parent adherence to PECS. If the child has advanced skills at baseline or previous experience with PECS, it served as a bridge to parental adherence as children progressed faster and smoother through the PECS phases, providing the parent with contact reinforcement. Participant 8 discussed the role of rapid PECS acquisition in contacting reinforcement, "the skill level of the child with the PECS can be you know I was saying before can be good ad can lead to good adherence because people around them are being reinforced by that".

Service delivery

Child service delivery factors involve the clinical milieu that the child is immersed in. Children often have multiple clinicians across multiple settings who provide treatment recommendations. Parental adherence is influenced by the congruence of these recommendations. Participant 4 best summarized how incongruent recommendations can hinder parental adherence, "consultants provide some strategies and the SLP who works lets say through school they have different ideas and sometimes there not all you know in contact".

Contrarily, participant 1 discussed the benefit and potential bridge of clinician communication and the diverse clinical milieu, " Ensuring… everyone is on the same page right and I mean that if the school is involved [and] other agencies or anyone else is involved trying to get them on the same page right using the same strategies".

Behavioral

The most common child factor discussed in all three focus groups was challenging behaviors. Many participants discussed the negative influence of challenging or frequent behaviors. Participant 4 best described this factor: "if there a high frequency of problem behaviors that's kind of interferes with like the skill acquisition what your trying to teach and sometimes you have to try to deal with the behaviors first"

Participant 2 discussed that in higher phases of PECS that "challenging behaviors begin to get in the way". Parental adherence to PECS recommendations becomes more difficult when children have behaviors that include "limited attention…it may be difficult enough just to get his attention and focus for a short amount of time".

An additional barrier is child response effort. Participants discussed that it is

easier for children to "learn to scream" to get what they want than to "go through the 20 pages in their [PECS binder] to pick up exactly what they want. So I think you know going back in to response effort of the child". On the other hand, many participants discussed child contacting reinforcement as a bridge to parental adherence. For instance, Participant 3 stated:

> "I think what you said earlier contacting reinforcement the child becoming more fluent with the use of PECS or maybe verbal language starts to surface because we've used PECS to you know get a communication system in place and now were seeing some vocalization".

Bridges and Barriers

Final thematic analysis revealed a total of 59 factors that influenced parental adherence to PECS recommendations(Table 4). A factor is operationally defined as any variable that can influence parental adherence, either positively or negatively. The use of the term factor in these results does not imply any reference to statistical procedures or relationships. Rather, this study was designed to reveal the elements (factors) that help/hinder parental adherence to PECS recommendaitons.A bridge was defined as a factor that positively influenced parental adherence to PECS recommendations, while a barrier was defined as a factor which negatively influenced parental adherence. There were 31 bridges that positively impacted parental adherence and 22 barriers that influenced non-adherence. In addition, there were 6 factors that were discussed as influences on parental adherence but were not explicitly stated as a bridge or a barrier. Of the factors, 47 were modifiable and 14 were non-modifiable. Modifiable factors were factors that could be directly addressed or changed by a parent or a clinician.

Table 4a.

Clinician Perceived Factors Impacting Parental Adherence to PECS Recommendations

Factors	**Bridge/ Barrier**	**Theme**	**Modifiable**	**Pattern**
Training	Bridge	Professional factors	Yes	Clinician
Level of experience/skills	Bridge	Professional factors	Yes	Clinician
Knowledge of clinical best practice/up to date approach with technology, with evidence based approaches	Bridge	Professional factors	Yes	Clinician
Pre-conceived notions lack of confidence in the parent	Barrier	Psychological attitudes and motivation	Yes	Clinician
Clinical expectations "fear of failing"	Barrier	Psychological attitudes and motivation	Yes	Clinician
Contact with reinforcement	Bridge	Psychological attitudes and motivation	Yes	Clinician
Initial education on PECS	Bridge	Knowledge mobilization	Yes	Clinician
Modeling	Bridge	Knowledge mobilization	Yes	Clinician
Hands on coaching	Bridge	Knowledge mobilization	Yes	Clinician
Clinician antecedent approaches	Bridge	Knowledge mobilization	Yes	Clinician
Assessing mediator skills	Bridge	Knowledge mobilization	Yes	Clinician
Providing written instructions	Bridge	Knowledge mobilization	Yes	Clinician
Clear instructions	Bridge	Knowledge mobilization	Yes	Clinician
Adaptable clinician/ individualized to parent	Bridge	Knowledge mobilization	Yes	Clinician

Table 4b.

Clinician Perceived Factors Impacting Parental Adherence to PECS Recommendations

Factors	**Bridge/ Barrier**	**Theme**	**Modifiable**	**Pattern**
Realistic recommendations	Bridge	Knowledge mobilization	Yes	Clinician
Parental empowerment	Bridge	Knowledge mobilization	Yes	Clinician
Irregular follow up visits	Barrier	Knowledge mobilization	Yes	Clinician
Parent training in multiple environments	Bridge	Knowledge mobilization	Yes	Clinician
Time constraints	Barrier	Service delivery	Yes	Clinician
Inter-professional conflicts	Barrier	Service delivery	Yes	Clinician
Clinician open communication	Bridge	Service delivery	Yes	Clinician
Addressing and troubleshooting potential challenges	Bridge	Service delivery	Yes	Clinician
Catering to the needs of parents	Bridge	Social	Yes	Clinician
Building Rapport	Bridge	Social	Yes	Clinician
Parents' unrealistic goals	Barrier	Psychological attitudes and motivation	Yes	Parent
Preconceived notions of BT	Barrier	Psychological attitudes and motivation	Yes	Parent
Parental motivation	Bridge	Psychological attitudes and motivation	Yes	Parent
Parental Buy in	Bridge	Psychological attitudes and motivation	Yes	Parent
Parental contact with reinforcement (progress, decreased Bx)	Bridge	Psychological attitudes and motivation	Yes	Parent
Clinician reinforces parent with social praise	Bridge	Psychological attitudes and motivation	Yes	Parent

Table 4c.

Clinician Perceived Factors Impacting Parental Adherence to PECS Recommendations

Factors	**Bridge/ Barrier**	**Theme**	**Modifiable**	**Pattern**
Incongruent parental values	Barrier	Psychological attitudes and motivation	Yes	Parent
Parental misunderstanding of PECS	Barrier	Knowledge mobilization	Yes	Parent
Lack of parental understanding PECS= voice	Barrier	Knowledge mobilization	Yes	Parent
Improper PECS implementation (loss of opportunities, moving ahead)	Barrier	Knowledge mobilization	Yes	Parent
Material preparation and empowerment	Bridge	Knowledge mobilization	Yes	Parent
Complexity of PECS (error correction, back prompter)	Barrier	Service delivery	No	Parent
Extra support	Bridge	Service delivery	Yes	Parent
Living situation	Not Specified	Social	No	Parent
How many kids (on or off spectrum of Autism)	Not Specified	Social	No	Parent
Work situations	Not Specified	Social	No	Parent
Geographical area	Not Specified	Social	No	Parent
Access to services	Not Specified	Social	No	Parent
Mental health of parent/possible diagnosis	Barrier	Social	No	Parent
Role of divorce and living in two households	Not Specified	Social	No	Parent
Siblings as communicative partners	Bridge	Social	No	Parent
Siblings' behaviors	Barrier	Social	No	Parent
Parental free time/ role of the parent	Bridge	Social	No	Parent
Lack of parental agreement/consistency	Barrier	Social	Yes	Parent
Parental education	Barrier	Social	No	Parent

Table 4d.

Clinician Perceived Factors Impacting Parental Adherence to PECS Recommendations

Factors	**Bridge/ Barrier**	**Theme**	**Modifiable**	**Pattern**
Language barriers	Barrier	Social	No	Parent
Parental support groups	Barrier	Social	Yes	Parent
Stigma of PECS	Barrier	Social	Yes	Parent
Child motivation	Bridge	Psychological attitudes and motivation	Yes	Child
Childs previous experience with PECS	Bridge	Knowledge mobilization	No	Child
Incongruent recommendations from multiple professionals	Barrier	Service delivery	Yes	Child
Communication between clinicians	Bridge	Service delivery	Yes	Child
Challenging behaviors and high-frequency	Barrier	Behavioral	Yes	Child
Child response effort	Barrier	Behavioral	Yes	Child
Child contact with reinforcement	Bridge	Behavioral	Yes	Child

Summary of Results

This thesis addressed three related research questions. Clinician expectations of parents implementing PECS with the mediator model varied considerably. The goal and expectation for most clinicians was perfect adherence to PECS recommendations. However, many clinicians were cognizant that one-hundred percent follow through was rarely achievable and on occasion felt that parents would error despite any training. Further, clinicians expectations were often shaped by past experiences. Like clinicians, parents had diverse expectations regarding the mediator model and PECS. There was a range of parent expectations regarding service delivery from therapist-implemented intervention to intensive parent training. Additionally, some parents wanted extensive

contact with clinicians while other were eager to implement independently. Further, parents expectations of the mediator model with PECS ranged from specific to unrealistic broad based goals for child outcomes.

In general, clinicians believed that PECS was complex and required some prior knowledge of behavioral principles. Clinicians reported that parents often had difficulty understanding error corrections, reinforcement and the use of back-prompters resulting in poor adherence to PECS recommendations. Further, parents did not understand that PECS was a stepwise process. Even if parents understood the stepwise nature, they were often impatient and wanted a quick fix. In addition, parents often did not understand that PECS functioned as a voice for their child. Not understanding behavioral techniques, the stepwise nature of PECS, and the function of PECS as a voice made it difficult for parents to adhere to clinician recommendations on PECS. Despite this complexity, clinicians reported a variety of bridges and barriers that helped or hindered parental adherence to PECS recommendations (Figure 1).

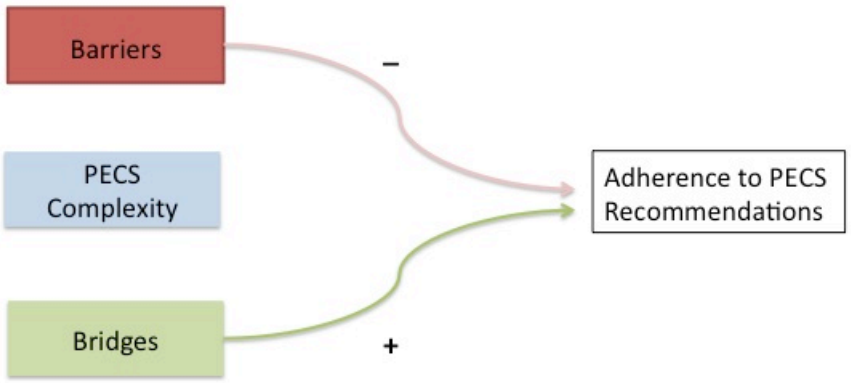

Figure 1. Relationship between PECS Complexity, Bridges and Barriers and Parental Adherence to PECS Recommendations

This study identified fifty-nine factors that influenced parental adherence to PECS recommendations. These factors were grouped into three patterns and six high-level themes. Patterns were: clinician, parent and child. High-level emergent themes were: (1) professional factors, (2) psychological (attitudes and motivations), (3) knowledge mobilization, (4) service delivery and follow through, (5) social, and (6) behavioral. The most discussed factors that impacted parental adherence to PECS recommendations were clinician training techniques and skills as well as parental understanding.

Discussion

Overview of study

This qualitative, focus group study investigated the perceptions of clinicians on parental adherence to PECS recommendations. The purpose of this study was to investigate factors that influence parental adherence to PECS implementation in the home environment. The research questions were: (1) What are clinician's expectations of parents implementing PECS within the mediator model of service delivery and what do they think parent's expectations are of them? (2) Do clinicians believe parents find it easy and/or difficult to adhere to the clinician's recommendations regarding the implementation of PECS with their child in their home environment? (3) Specifically, what factors contribute to parental adherence or non-adherence to clinician recommendations on the use of PECS with their child?

Clinician experiences, attitudes and beliefs were explored. A total of 3 focus groups including both BTs and SLPs were conducted consisting of approximately six hours of in-depth discussion. There was consistency between all three focus groups and between BTs and SLPs in identifying clinician expectations, parental expectations, parental ability to implement PECS recommendations and factors that influenced parental adherence to recommendations on the implementation of PECS. Recursive constant comparison analysis identified six high-level emergent themes: (1) professional factors, (2) psychological (attitudes and motivations), (3) knowledge mobilization, (4) service delivery and follow through, (5) social, and (6) behavioral. In total, 3 major patterns were identified: clinician factors, parental factors, and child factors. Codes relating to expectations were used to answer research question one, while codes relating to PECS

implementation were used to answer research question two. This study identified diverse clinician expectations of parents and parent expectations of the mediator model and PECS. In general, clinicians believed that PECS was complex and difficult for parents to implement correctly. Despite the complexity of PECS implementation, clinicians identified a number of factors that helped or hindered parental adherence to PECS recommendations. A total of 59 factors including 31 bridges, 22 barriers, and 6 factors not otherwise specified were identified. Clinicians believed that parents were able to adhere to recommendations when a number of the bridging strategies were used.

Complexity of PECS

This study demonstrated that clinicians believed that parents found implementation of PECS recommendations complex. Clinicians believed that parents did not have the requisite knowledge of Applied Behaviour Analysis and could not grasp concepts including the specific error corrections. Further, parents often did not understand or were too impatient for the step-wise nature of PECS. The literature is mixed regarding the ability of clinicians to train others on PECS implementation. Researchers have documented the complexity of PECS (Barnes et al., 2011; Sulzer-Azarof et al., 2009). Barnes et al. (2011) examined the effects of a training program using verbal instruction, specially designed handouts and an instructional video on three direct care staff at an adult day program specializing in ASD. Despite a minimum of 1.5 years of experience working with children with ASD, none of the three employees were able to master phases 1, 2, 3A, and 3B of PECS. A number of the most commonly missed steps were related to ABA principles including ensuring that the reinforcer was preferred,

correctly scoring data within 5 seconds and conducting reinforcer assessments after every 5 trials or less; however, many errors were also related to lack of preparation.

Criticisms of the Barnes et al. (2011) study include the fact that Behavior Skills Training Techniques were not used and the fact that participants did not have adequate opportunities to master skills. Furthermore, Howlin et al. (2007) demonstrated only modest short term effectiveness of a 2-day PECS workshop plus 6 half-day training sessions by expert consultants in training teachers who worked in ASD classrooms, but who had never been trained in PECS. In Howlin's study, students with minimal functional language in ASD classrooms where teachers underwent training had increased PECS initiation and usage immediately post-treatment compared to students in classrooms where training was not undertaken. Despite these early improvements in PECS usage, improvements were not maintained at late follow up and there were no noted improvements in frequency of speech or language test scores. Unfortunately, this study did not test treatment integrity or teacher adherence to recommendations; however, one hypothesis provided by the authors for the lack of lasting benefit was that adherence wad not maintained.

Contrary to the results of the Barnes et al., (2011) and Howlin et al. (2007) studies, Rosales et al. (2009) demonstrated the effectiveness of a program designed to facilitate PECS implementation on three individuals with no previous training on AAC systems. Unlike the previous studies, the program assessed by Rosales et al. (2009) was rooted in Behavioral Skills Training and included a review of the PECS manual, videotapes, written instructions, verbal instructions, checklists, modeling, rehearsal and feedback. All three participants mastered the majority of criterion in all phases. The only

task the study participants had difficulty mastering was related to Applied Behaviour Analysis and involved participants fading themselves out based on learner responses in Phase 2. These authors also demonstrated that training was efficient only requiring a total time commitment of 131 to 208 minutes to reach skill mastery which was maintained at follow up. Similar to Rosales et al., Wood et al. (2007) demonstrated the ability of four previously untrained direct care staff to adhere to and master PECS recommendations using Behavior Skills Training skills including written instructions, modeling, hands on rehearsal and feedback.

As demonstrated in this current study as well as in the study performed by Barnes et al.(2011), PECS can be difficult for non-experts to implement. Non-experts have difficulty with techniques including reinforcement, error correction and data collection. Despite this inherent complexity, strategies have been developed to facilitate skill mastery and adherence to recommendations. Many of the strategies identified by Rosales et al. (2009) and Woods et al. (2007) were echoed during focus group discussion in this current study. These bridges and barriers will be explored in more depth in the subsequent sections.

Contextual framework for clinician perceived clinician factors as bridges and barriers to parental adherence to recommendations to PECS implementation

The current study identified 27 clinician factors affecting parental adherence to PECS recommendations. These findings are similar to findings previously reported by Pappas et al., (2008), Allen & Warzak (2000) and Isaacs et al. (2008).

Professional factors

Professional factors identified in this current study included clinician training, level of experience/skills, knowledge of clinical best practice, and up to date approach with integration of technology and evidence based practices. Similar to this current study, clinician training and experience has been shown in previous studies as bridges to parental adherence (Allen & Warzak, 2000; Isaacs et al., 2008; Pappas et al, 2008). It is clear that more experienced professionals can be more adaptable and can employ tested techniques that promote parental understanding of and adherence to treatment recommendations. As such, it is important to implement professional development and mentorship programs to promote evidence-based practice and to disseminate experience to newly trained professionals. This technique will allow young new professionals to learn from more experienced individuals. Professional standards mandating continuing education would also ensure knowledge of evidence-based techniques. Further, teaching clinicians how to use modern technology can help facilitate training as it has potential to make training practices more user-friendly.

Psychological factors

Psychological factors in this current study included clinician pre-conceived notions and lack of confidence in parents, clinical expectations such as a fear of failing, and whether clinicians received reinforcement based on parent and/or child progress. Similar to these results, Pappas et al. (2008) reported that SLP beliefs on parental involvement influenced SLP recommendations to parents, and that lack of therapist confidence in parental involvement was a barrier to providing parental recommendations. Isaacs et al. (2008) also identified contact to reinforcement as a bridge to parental adherence. One potential explanation for these findings is that fear of failing and lack of

confidence can impact clinician effort and motivations, negatively impacting knowledge mobilization technique and ultimately decreasing parental adherence. When clinicians are motivated by past positive experiences or contact with reinforcement, their commitment to parental training programs may be enhanced increasing the likelihood of parental adherence. Cognitions including fear of failing and lack of confidence can be addressed through clinician mentorship programs.

Knowledge mobilization factors

Knowledge mobilization factors in this current study included parental misunderstanding of PECS, complexity of PECS, initial education on PECS, behavioral skills training approaches, providing antecedent techniques, adaptability of clinician to parental needs, assessment of mediator skills and parental empowerment. The behavioral skills training technique factors identified were providing written instructions, providing clear instructions, modeling, hands on coaching, regularity of follow up visits, and parent training in multiple environments. This present study is consistent with previously published studies by identifying a variety of clinician training techniques as bridges to parental adherence. Commonly discussed techniques include rapport building (Allen & Warzak, 2000), assessing mediator skills (Isaacs et al., 2008), providing clear and detailed instructions (Allen & Warzak, 2000), modeling (Isaacs et al., 2008), parental observation (Isaacs et al., 2008), BT ability to empower parents (Isaacs et al., 2008), providing feedback, and the use of simple language to describe intervention as bridges to parental adherence (Allen & Warzak, 2000). Allen and Warzak (2000) discussed that clinicians should train parents explicitly from the outset of treatment. They should provide clear instructions in training across a variety of settings and exemplars. Allen

and Warzak (2000) discussed reducing interventions into "manageable, easy-to-learn steps". This study continued to discuss that if these small steps remain too complex that it is necessary to consider changing the intervention (Allen & Warzak, 2000). Given this, it would be ideal for clinicians to follow a standardized manual for parental training on PECS, which stresses these behavioral skills training approaches. An ideal parent training manual on PECS would follow an approach outlined in an article written by Kaiser and Hancock (2003).

Kaiser and Hancock (2003) developed a set of recommendations to aid clinicians in training parents as mediators. These authors provided detailed descriptions on how to prepare parents to become mediators and on parent training techniques. These techniques included explaining a conceptual framework for intervention, developing goals with parents, rapport-building, adapting interventions to meet parent and child needs, providing clear and detailed instructions, presenting corrective feedback, and teaching to promote generalization to multiple settings. These authors suggest developing strategies to assess parent implementation, evaluating parent and child outcomes, and providing additional services to facilitate intervention. These suggestions by Kaiser and Hancock (2003) are similar to suggestions discussed in the present study. Training clinicians using Kaiser and Hancock's approach can ensure sound knowledge mobilization techniques, maximize parent understanding at the time of training, and promote parental adherence to recommendations.

Furthermore, the present study identified that parents have varied needs and that adapting teaching strategy to cater to these needs facilitated adherence. Adaptability involves assessing parental needs and goals and developing protocols that are congruent.

Adaptability also involves assessing when an intervention is not working or being adhered to and modifying it to better meet a parent and/or child's needs. Although the present study and others (Allen & Warzak, 2000; Isaacs et al., 2008) report that clinician adaptability serves as a bridge to parental adherence, Isaacs et al. (2008) identified that many parents did not think clinicians were adaptable and that this negatively impacted their adherence to recommendations. Given this, it is crucial to ensure that clinicians are adaptable. Developing guides and strategies for clinicians will allow flexibility and promote adherence.

Service delivery factors

Service delivery factors in this current study included clinician time constraints, inter-professional conflicts, open communication among involved clinicians, addressing and troubleshooting potential challenges. This study's results suggest that clinicians need to communicate with each other and provide consistent recommendations to enhance parental follow through. Similar to the present study, Pappas et al. (2008) discussed the impact of SLP time constraints and SLP workplace. These authors expanded upon these factors and discussed inflexible work environments as a major barrier to adherence. Additionally, Isaacs et al., (2008) identified finite BT time as a barrier because it caused long waiting lists and short service time. Isaacs et al., (2008) also concluded that frequent visits promoted parental adherence. Additional clinician factors that were not identified in the present study but have been previously identified include the need for a clinician to undertake roles besides parent trainer (Isaacs et al., 2008) and poorly controlled teaching environments (Allen & Warzack, 2000). Clinician time and resources are important as it impacts the amount of time a clinician spends giving recommendations and training

parents. When there are time or resource constraints, clinicians might use poor technique and not provide detailed recommendations. Clinicians may have large case loads and may be unable to dedicate sufficient time to each client. If a clinician is stressed or overwhelmed due to their case load, they may be less committed to their job and subconsciously provide lower quality service. Further, when a clinician's time is limited they might not go to professional development meetings, which would prevent uptake and delivery of best current practice techniques. In an ideal world, one could fund more clinicians to provide training to parents so that a single clinician can have a smaller case load and dedicate more time to train families. As such, they would be better able to assess parental needs and design recommendations most suitable for that client and provide effective parent training. In the current economic environment, funding is limited therefore this may not be feasible and strategies need to be developed to optimize the use of few available resources. Efficiency can be generated by utilizing validated manuals and techniques that are proven to enhance parental understanding.

Social factors

Social factors in this current study included clinician catering to the needs of parents and building rapport with parents. As previously mentioned, Kaiser and Hancock (2003) reported that it is essential to interact with parents, identify their needs, and build rapport to develop protocols that will optimize parental adherence and child outcomes. These social bridges advance the theme of knowledge mobilization and ensure that strategies and protocols are congruent with a parent's social environment. During professional development meetings, sensitivity training and rapport-building training can

be addressed. Further, training strategies that address adaptability will allow clinicians to address these social factors.

Contextual framework for clinician perceived parental factors as bridges and barriers to parental adherence to recommendations to PECS implementation

The present study revealed 27 parental factors which clinicians believed contributed to parental adherence to PECS recommendations.

Psychological factors

Parental psychological factors in this current study included unrealistic goals, preconceived notions about BTs, motivation, buy in, contact with reinforcement, social praise from the clinician to the parent, incongruent parental values, and parental mental health. Similar to this study, Kazdin et al., (1997) found that poor parental perceptions and parental psychiatric illness negatively impacted parental adherence. Moore and Symons (2011) further discussed the role of parental cognitions as factors influencing parental adherence. Major psychological factors identified included parental perceived effectiveness of the intervention, perceived confidence, and perceived acceptance of child in family in community activities. Additionally, Allen & Warzack (2000) expanded on psychological barriers to parental adherence. The authors reported similar psychological barriers to parental adherence including parental cognitive impairment, parental lack of motivation, past experience with immediate improvements to medical interventions, and poor clinician reinforcement for parent rule following. These results were confirmed by Isaacs et al., (2008) in a study that identified parental buy-in to the intervention, buy-in to

the mediator approach and intervention congruity as factors contributing to parental adherence.

It is clear that motivated parents who believe in the intervention are more likely to adhere to PECS recommendations. Clinicians should address parental attitudes and beliefs at the outset. Clinicians need to improve parental buy-in by clearly stating PECS objectives and outlining potential benefits. Clinicians also need to enhance parental motivation through reinforcement to increase parental adherence. Allen & Warzak (2000) developed strategies to address parental motivation, parental need for a "quick-fix", and need for parental reinforcement. These authors suggested creating early behavior changes as reinforcers to increase parental contact with reinforcement and motivation. For example, these authors suggested defining an extinction burst or aversive child behaviors as an early marker of progress. When parents understand that increased behaviors are expected before a decrease, they might be more motivated to continue adhering to the intervention.

It is impossible to modify parental cognitive impairment or psychiatric disease at the time of parent training. Instead, the clinician needs to provide recommendations that are easily understood and that are congruent with parental abilities. This can involve providing simpler instructions with pictures, providing videos and using other forms of training to meet parental needs. Allen and Warzak (2000) suggested that clinicians need to address parental factors and make interventions congruent with parental cognitive ability and provide links to community and mental health services. Allen and Warzak (2000) also suggest changing interventions as needed based on parental cognitive impairment.

Knowledge mobilization factors

Parental knowledge mobilization was a major theme that was discussed. Knowledge mobilization factors in this current study included lack of parental understanding of PECS as a voice, parental improper PECS implementation, material preparation and parental empowerment. Isaacs et al. (2008) discussed the importance of parental knowledge of the chosen intervention, empowerment through education, and understanding the approach to implementation. Similar to Isaacs et al. (2008), this current study reported the importance of parental knowledge and understanding; however, factors in this current study were specific to parental misunderstanding of PECS. Commonly discussed factors were parents not understanding PECS as a voice for their child, and failure to properly implement PECS in multiple environments.

It is interesting to note that in this current study, clinicians identified parental lack of knowledge of PECS as a major parental factor influencing adherence, while at the same time discussing the importance of parental education and training by clinicians as a major clinician factor. This finding would suggest that clinicians should thoroughly assess parental understanding of PECS and provide simple, detailed instruction of proper implementation at the initial meeting. This can include providing information that PECS is a gradual step-wise form of communication and that rapid improvement is unlikely. Furthermore, parents must be taught from the outset that PECS is a communication system equal to a voice (Frost & Bondy, 2002). If parents understand that PECS requests are no different from verbal requests, they may be more likely to follow through on recommendations as they are motivated to respond to their child's needs.

Service delivery factors

Service delivery factors in this current study included the complexity of PECS and the use of extra support to reduce response effort. Many participants in this current study discussed the complex and intricate nature of PECS as a barrier to parental adherence. They discussed the confusing nature of error correction and the requirement of a back prompter in early phases of PECS implementation. Similar to this current study, Allen and Warzak (2000) discussed skill complexity as a variable in providing parents with recommendations. These authors suggested breaking down complex interventions into easy-to-learn, step by step instructions to increase parental follow through. Similar to Allen and Warzak (2000), this current study identified simple, step by step instructions as a bridge to parental adherence to PECS recommendations. Furthermore, clinicians in this study discussed the use of back prompters and extra support as a means to facilitate service delivery of PECS. Allen and Warzak (2000) confirm this concept and discuss using community services including community groups, friends and relatives as supports to increase parental adherence. A novel approach introduced in this current study involved using siblings as back prompters and communication partners during PECS implementation. These strategies increase parental supports, improving social factors and ultimately service delivery.

Social factors

Social factors in this current study included parental living situation, how many kids were involved on or off spectrum of Autism, work situations, geographical area, access to services, role of divorce and living in two households, siblings as communicative partners, siblings' behaviors, parental free time/ role of the parent, lack of

parental agreement/consistency, parental high-level education, language barriers, parental support groups, and the parental perceived stigma of PECS. Similar to these findings, Kazdin et al., (1997) identified social barriers to parental adherence to behavioral treatment including poor relationship between parent and therapist, parental stressors, socio-economic disadvantage, younger parents and single parents. In addition, Moore and Symons (2011) confirmed spousal disagreement as a barrier to parental adherence. Allen and Warzak (2011) further discussed similar demographic parental barriers to parental adherence. These authors reported social barriers including parental restricted economic resources, social isolation, and parental perceived stigma of the intervention. Also similar to this current study, Isaacs et al., (2008) reported language barriers as a social factor influencing parental adherence.

As mentioned above, the present study was one of the first to identify the involvement of siblings as communicative partners in the use of PECS. This current study reported siblings acted as both bridges and barriers to parental adherence to PECS recommendations. If siblings could act as mediators or supports for PECS delivery they were identified as a bridge to parental adherence. However, if siblings interfered or had challenging behaviors of their own they were identified as a barrier to parental adherence to PECS recommendations.

Allen & Warzak (2000) suggested strategies to reduce the impact of parental social barriers. These authors suggested that clinicians need to make interventions congruent with parental time availability, ability to afford interventions materials, and availability of multiple caregivers. These authors also addressed modifying parental demographic factors by involving parental support groups and social service agencies. To

address these potential barriers it is important for the clinician to take a detailed social history on initial assessment. This will allow the clinician to adapt a PECS training program which will be congruent with the parents social environment, while at the same time, directing parents to community resources that can address social needs.

Contextual framework for clinician perceived child factors as bridges and barriers to parental adherence to recommendations to PECS implementation

This study included 7 child factors influencing parental adherence to PECS recommendations.

Psychological factors

Child motivation was the only psychological factor identified in this current study. A through review of the literature did not identify child motivation as a factor relating to parental adherence to recommendations. Bondy and Frost (1994) suggest that child motivation is key to positive outcomes in the use of PECS. One can hypothesize that parents of children who are more rapidly and fluently learning to use PECS will be more motivated to adhere to recommendations.

Knowledge mobilization factors

Child's previous experience with PECS was the only knowledge mobilization factor identified within this current study. A thorough review of the literature did not reveal any similar knowledge mobilization factors, which is likely due to the fact that no previous study has investigated factors influencing parental adherence to PECS specific recommendations. A possible explanation for child previous experience with PECS or other interventions is higher baseline or more rapid learning curve. Rapid improvement in

communication and behavior provide both parents and children with contact to reinforcement and motivates parents to adhere to recommendations.

Service delivery factors

Service delivery factors in this current study included the incongruent recommendations from multiple professionals and open communication between professionals across environments. According to Isaacs et al. (2008), incongruent recommendations of multiple professionals was reported as a barrier to parental adherence, whereas Moore and Symons (2011) identified whether the child was currently receiving services as a bridge to parental adherence. Similarly to Isaacs et al. (2008), this current study noted incongruent recommendations as a factor negatively impacting parental adherence. A possible explanation for these opposing results of these 3 studies might be the congruent or incongruent recommendations and intervention being portrayed by professionals. If all professionals involved communicate and present parents and children with uniform and realistic recommendations and strategies, this might promote parental adherence. On the other hand, if parents are receiving mixed messages and varied strategies they can become confused or less motivated, thus becoming less likely to adhere. To address inter-professional conflicts as a barrier, this author recommends communication between all involved clinicians early in the intervention process.

Behavioral factors

Behavioral factors in this current study included the child's challenging and highly frequent behaviors, child response effort and child contact with reinforcement. Isaacs et al. (2008) also identified children's challenging behavior as a barrier to parental

adherence on behavioral recommendations. According to Isaacs et al. (2008), parents reported that child's challenging behaviors made it difficult to follow recommendations because they became tired and defeated while dealing with behaviors. Similarly, Moore and Symons (2011) identified the total number of child behaviors and the difficulty of child behaviors as barriers to parental adherence. As such, if other professionals such as psychiatrists or psychologists provide treatments that reduce problem behavior frequency and intensity, parents might be more likely to implement PECS appropriately. It is reasonable to assume that it might be easier for parents to adhere to recommendations when child challenging behaviors are minimized. For example, if a child is aggressive towards a parent, the parent might need to escape or address the behavior and will be less likely to follow through with PECS recommendations in that moment. As a strategy to promote parental adherence, especially in times when a child is becoming escalated or frustrated, the clinician should inform the parent from the outset that PECS is a valuable intervention that reduces behaviors through functional communication, and that this might be the most appropriate way for the parent to reduce problem behaviors now and in the future. It is the role of the clinician to educate and help parents understand how PECS can reduce these challenging behaviors. Further, training parents in ABA techniques can provide parents with strategies to address problem behaviors making it easier to implement PECS recommendations.

The other behavioral child factors identified were not previously noted within the literature. Child response effort was identified as a barrier to parental adherence and child contacting reinforcement was identified as a bridge to parental adherence in this current

study. Similar to child motivation, one can hypothesize that children will be more likely to use PECS frequently when it requires less child response effort than alternatives and when they are receiving immediate reinforcement. If children are using PECS more frequently and appropriately, parents will be more motivated to adhere to clinician recommendations.

Strengths

This study is the first study that investigates clinician perceived bridges and barriers to parental adherence on PECS recommendations. Strengths include this study's qualitative nature through in-depth analysis, the use of focus groups and the many checkpoints to ensure trustworthiness.

Qualitative research permitted the in-depth analysis of clinician perceived parental adherence to PECS recommendations that could not have been generated by quantitative means. It allowed for a holistic, descriptive and "insider" perspective (Cresswell,1998; Johnson & Christensen, 2008). There is only emerging data on potential bridges and barriers to parental adherence on PECS recommendations, and there is no known validated quantitative metric. This qualitative design involved a naturalistic approach that developed an in-depth analysis of clinician perceived bridges and barriers to parental adherence to PECS recommendations. This design captured clinical expert experiences, attitudes, and behaviors using direct quotations and verbatim transcription (Cresswell, 1998; Johnson & Christensen, 2008). Qualitative analysis allowed for context sensitivity where results were immediately put into social and temporal context (Johnson & Christensen, 2008). The iterative process of qualitative nature allowed for in-depth

discussion of emerging themes that were not known prior to study initiation. If this were a quantitative study, all questions would have needed to be defined in an *a priori* manner (Pope & Mays, 2006).

The use of focus groups further enriched the data obtained. Stewart and Shamdasani (1990) define the many advantages of focus group studies. The present study involved direct interaction between the moderator and participants allowing for the opportunity for clarification of responses, for probing of responses, for follow-up questions, and the use of summary statements to ensure statements were not taken out of context. This design also encouraged "snowballing" where a comment triggered responses from multiple group participants. Stewart and Shamdasani (1990) define this as a synergistic effect where snowballing provides the development of ideas that would not have otherwise arisen using other methods. Synergism and snowballing allowed for the collection of deeper, richer, and more detailed information than would have been available using other methods (Stewart & Shamdasani, 1990).

This study integrated various checkpoints in order to ensure trustworthiness of the data. The trustworthiness analysis of this study followed the validated approach of Guba and Lincoln (1981). This study used safeguards to ensure trustworthiness by evaluating credibility, fittingness, and auditability. Safeguards to prevent against invalid confounding factors and a degree of structural corroboration were used to ensure credibility, increase rigor and improve validity. Member-checks were performed by offering study participants the opportunity to review their focus groups transcript to ensure transcription was accurate and representive of what was discussed during their focus group. Additionally, an external auditor reviewed all transcripts and thematic

analysis to ensure sound methodology. This auditor was in strong agreement with the coding of the transcripts of each focus group, and the amalgamation of codes across the three patterns. Additionally, during focus groups there were 2 members of the research team present to ensure procedural compliance. The second researcher was also used to ensure that thematic analysis was representative of focus group discussions (Guba & Lincoln, 1981).

Limitations

Although the study was designed in a technically sound manner, with many checks to ensure trustworthiness, a number of methodological limitations arose. These limitations were recruitment challenges, focus group challenges, and assessment challenges.

This study evaluated clinician-perceived factors that influence parental adherence to PECS recommendations, as opposed to clinician and parent perceived factors. Initially, this study intended to capture both parent and clinician opinions as this would have provided richer data that would have been more clinically significant. Having both parent and clinician opinions, would have allowed us to compare the issues raised by both groups, and determine the degree to which their experiences are similar or different. Also, including parents in this study, might have yielded different perspectives on clinician bridges and barriers. Also, the involvement of parents could have generated richer and more detailed factors or corroborated those presented by clinicians. By including both parents and clinicians, one could have compared perspectives and identified consistencies and gaps. This study initially intended to recruit parents through advertisement including

posting study flyers on Autism Ontario and other support group websites.
Over a two year period, this recruitment strategy only generated one interested parent. This parent was not eligible for the study as she was provided with recommendation on an AAC device other than PECS. Subsequently, a number of strategies were employed to attempt to increase recruitment. GTA Autism service organization directors were contacted and provided detailed information on this study. Several organizations were asked to disseminate information. Flyers were sent by service organization directors directly to interested parents.

It is clear that this study failed to generate parental interest. A precursor study, Isaacs et al. (2008) was able to generate significant parental interest and was able to produce focus groups involving a total of 17 parents and 10 BTs. Unlike this current study, the study by Isaacs et al. (2008) was conducted in partnership with a single clinical service organization from the initial study design through to recruitment and data analysis. This present study would have potentially been able to recruit parents if a similar strategy was employed. An explanation for this difference might have been due to lack of agency buy-in as it was not specifically evaluating agency protocols or programs. If an agency was involved in this study's design, a prospective recruitment process could have occurred where all parents currently receiving recommendations on PECS implementation were invited to participate. Despite this, the current recruitment strategy was favored as it collected data from participants across the GTA. The results of this study were not limited to a single agency and represent experiences from a variety of unique clinician. If all clinicians were recruited from the same agency, they would have had similar training, operational manuals, and oversight. As such, bridges and barriers to

parental adherence to PECS recommendations might have been unique to that agency. Although qualitative data is not meant to be representative of the entire community, recruiting clinicians broadly increased the breadth of discussion.

Similarly, this study failed to recruit large number of clinicians. As such, focus groups contained only two to three participants and were not equally weighted with BTs and SLPs. The reason why focus groups contained three or fewer participants was that they were conducted around the time that subjects expressed interest. This was done to maintain clinician interest and ensure maximal study enrollment. The small focus groups also accommodated busy clinician schedules.

As previously mentioned, focus groups typically involve 6-12 participants across three total focus groups. As discussed previously, two qualitative methodologists, Morgan and Krueger, both define and validate the use of "mini-focus groups" with fewer than six participants per group (Krueger, 1994; Morgan, 1997). This study involved two participants in one out of the three focus groups, which has not previously been advocated by Krueger or Morgan. This can be considered as a limitation as it is unclear of the type or richness of discussion provided. Discussions could have involved different levels of synergisms, snowballing, and divergence than typical larger focus groups. Ideally, this study would have had larger focus groups but this was not possible based on low clinician interest.

One might argue that this study should have been limited to board certified BTs. Board certified clinicians receive extensive training and have a professional obligation to involve parents as mediators. This study did not limit participants to being board

certified. It is clear from personal and professional observations that non-board certified clinicians provide PECS recommendations to parents. By including some non-board certified clinicians this study provides more naturalistic and holistic data and is more clinically significant. This study sought to include clinicians who are providing PECS recommendations to parents and are working in the field, regardless of professional designation.

Further, this study did not directly ask clinicians what level of training they received on the mediator model and PECS. One can hypothesize that clinicians with formal training might employ different and more evidenced-based techniques to provide recommendations to parents on PECS. Formal training likely affected the clinicians ability to both implement PECS with fidelity and train parents to do so. The opinions and beliefs expressed by participants might have been influenced by their training. Despite not documenting training, these results are still valid because the study participants are the clinicians in the field training parents and they are the ones most familiar with the factors affecting service delivery. If this study was limited to only formally trained clinicians, it would not necessarily be applicable to the real world where non-trained clinicians often train parents as mediators.

Qualitative research is meant to be hypothesis-generating. As such, it provides observational information that can not be generalized to a larger population. It provides experiences of the study participants only. Further quantitative studies will need to be conducted to ensure the findings are generalizable and representative of all clinicians. Qualitative research also generates bias not seen in other forms of research. The researcher is embedded in data generation and analysis. As such, researcher objectivity

and reliability are often suspect (McMillan & Schumacher, 1997). The researcher may purposely or accidently direct discussion during focus groups to generate specific themes through rapport building. Alternatively, the researcher may manipulate the data coding process. This study involved internal and external checks to prevent these forms of bias; however, it is possible that some small elements of bias went unchecked. Focus group participants could also sway and influence the discussion. Although synergism and snowballing are potential strengths of focus group research, they can also serve as a limitation. Discussions are not necessarily independent and participants might discuss findings due to pressure from other participants.

Future Directions

This study generated many interesting hypotheses that need to be followed up with future research. Future studies could involve three main phases to further examine parental adherence to PECS recommendations. The first phase involves conducting a study including parental focus groups will generate further clinically significant factors that help or hinder parental adherence to PECS recommendations. As previously mentioned, partnering with Autism service organizations might provide improved recruitment. A quantitative study should be conducted in phase 2, to further validate the factors that arose during focus groups. A simple study design could involve Likert questionnaires with each factor rating importance on a scale of 1-10. This questionnaire could be mailed to clinicians and parents in order to define the perceived importance of each factor. Phase 3 would develop a Behavioral Skills Training (BST) approach to clinician recommendations based on the current studies findings. The study would evaluate parental adherence to clinician recommendations on PECS comparing baseline

to BST training. Parental adherence to PECS recommendations can be measured using parent-reported surveys, direct observation or video-coding.

This present study and the proposed future studies are directed at examining parental adherence. Future studies must also be directed at evaluating child outcomes relating to parental adherence to PECS recommendations. For example , in addition to using a single case design to evaluate the acquisition of PECS by the child, integrity checks (e.g. parent checklists, live observations of implementation) could be implemented to assess the relationship between parental adherence and skill acquisition.

In regards to parental expectations, a future study can investigate parental expectations prior to mediator model training on PECS implementation in more detail. A questionnaire or focus group technique could be used. Additionally, a follow up study investigating if mediator model training on PECS met parental expectations could be conducted.

This study identified that clinicians believed that PECS was complicated for parents to implement and follow through on recommendations. An interesting future study would investigate if parents believed that PECS was complicated, which components were most difficult to learn, and what could be done in the future to facilitate PECS understanding and adherence.

Implications

This qualitative, focus group study identified 59 factors affecting parental adherence to PECS recommendations which can be subdivided into 3 major patterns and 6 high level themes. The patterns were clinician factors, parent factors and child factors.

The high level themes were professional factors, psychological factors, knowledge mobilization factors, service delivery factors, social factors and behavioral factors. Factors which positively influenced parental adherence to PECS recommendations were termed bridges, and factors which negatively influenced parental adherence to PECS recommendations were termed barriers. Factors can additionally be divided into modifiable and non-modifiable factors. Modifiable factors were factors that could be addressed and modified by a parent or clinician. This study identified 47 modifiable factors. Strategies to address these factors should be directed at increasing bridge factors and decreasing barrier factors with the ultimate goal of improving parental adherence to PECS recommendations. Non-modifiable factors are factors that are intrinsic to an individual and can not be easily changed. These factors cannot be addressed by behavioral change techniques. Instead, one must develop strategies that account for these factors by adapting parent training techniques to accommodate them. This study identified 14 non-modifiable factors. Based on these factors, recommendations to promote parental adherence to PECS have been hypothesized earlier in this discussion.

This study demonstrated that clinicians believed that parents found PECS complex and difficult to implement. This complexity is related to the vastness of the PECS manual, the stepwise approach to PECS implementation and the use of Applied Behavioral Analysis techniques including backward chaining and reinforcement. This complexity made it difficult to adhere to PECS recommendations. Despite this inherent complexity, a variety of modifiable factors were identified that can help facilitate parental adherence to PECS recommendations. In fact, the majority of bridges and barriers identified were related to parental knowledge and understanding or clinician training

technique. If a clinician is able to identify parental knowledge gaps, he/she can address these to ensure understanding and promote adherence. Many bridge factors identified in this study involved clinician educational and behavioral skills training techniques. Developing a comprehensive guide for clinician education on the mediator model and PECS can provide clinicians with the requisite knowledge and skills to train parents effectively in the implementation of PECS. Figure 2 demonstrates how 36 of the 59 factors are inter-related and can be addressed using this clinician training manual.

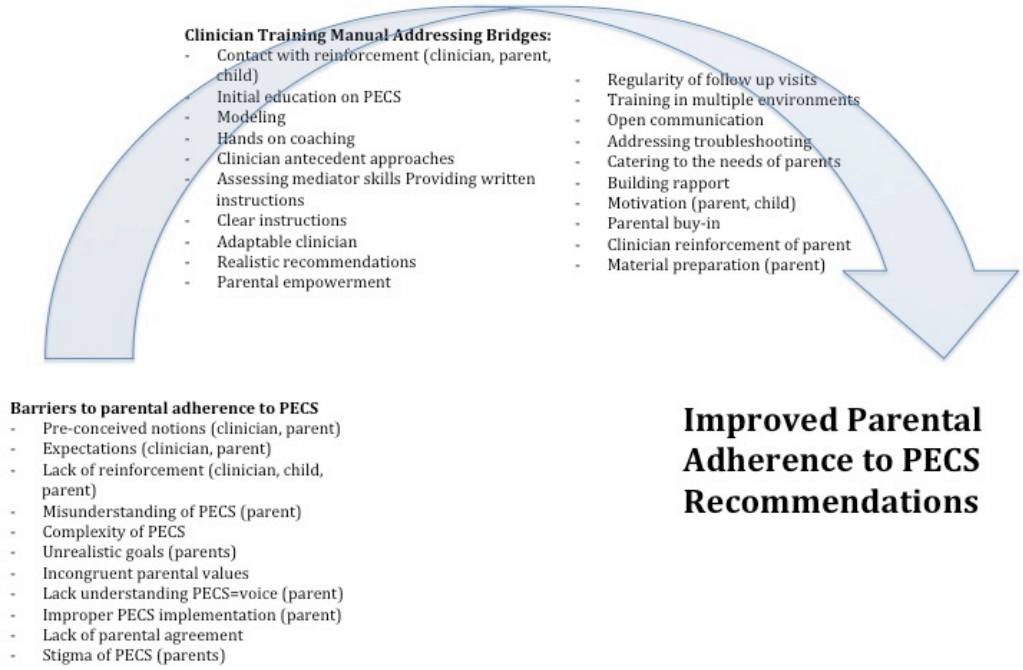

Figure 2. Model demonstrating the role of a manual to optimize parental adherence to PECS recommendations

This manual would specifically discuss the practicalities of initial assessment as well as parental training on PECS. Initial assessment would be aimed at identifying and addressing parental cognitions, expectations, understanding of PECS and parental baseline mediator skills. This assessment would clearly define what the mediator model does and does not provide and can help align clinician and parental expectations from the

outset. In turn, this might improve clinician and parent satisfaction, which can ultimately affect training technique and/or parental adherence. Following initial assessment, the clinician must optimally train parents on PECS implementation. The manual would discuss the use of behavioral skills training techniques and other clinician recommended strategies to enhance parental understanding of recommendations. Examples of written instructions, modeling, hands on teaching, antecedent approaches will be provided for each phase of PECS. Additionally, information on how to adapt PECS training to specific parent needs will be addressed.

To design an optimal manual, further consultation is needed to ensure that the factors identified in this study are relevant to parents and generalizable beyond the focus group participants. This will involve further parental focus groups and subsequent questionnaire studies based on the results.

Once factors are identified, a manual will be designed that incorporates strategies presented by Kaiser and Hancock (2003) and Rosales et al. (2009). It will discuss and address parental understanding, perceptions and expectations while promoting Behavioral Skills Training techniques. In addition to potentially being effective at improving adherence, this strategy can also be effective at managing clinician time constraints and the to professional resources that parents experience. As demonstrated by Rosales et al. (2009), Behavioral Skills Training in PECS involving videotapes, written and verbal instructions, checklists, modeling, rehearsal and feedback only required total training times ranging from 131 to 208 minutes to reach skill mastery which was maintained. The addition of the initial assessment phase will require additional time commitments but should not be overly difficult for clinicians.

Kaiser and Hancock (2003) additionally advocate for professional training of all parent educators to address the factors noted above. This professional training advocates for course work, a child practicum, a parent practicum and an apprenticeship to parent teaching prior to clinicians training parents as mediators. Combining a manual and course training work will further enhance clinician training of parents and maximize adherence.

Conclusions

This was the first study investigating clinician-perceived factors effecting parental adherence to PECS recommendations. This study employed a qualitative, focus group methodology and constant comparison analysis to address three clinically relevant, socially significant research questions. This study identified diverse clinician and parent expectations on the mediator model and PECS. Participants discussed the complexity of PECS and the difficulty parents had in adhering to PECS recommendations. Finally, this study identified 59 clinically and socially significant factors that serve as bridges and barriers to parental adherence. These factors are similar to factors previously identified in parent training literature. Future focus group studies need to be conducted to confirm that clinician perceived factors for parental adherence are similar to parental perceived factors. Additionally, large scale studies need to be conducted to ensure validity and to investigate the impact of parental adherence on child outcomes. Based on the results of this study and future studies, a manual and training program could be designed to optimize clinician training of parents to ultimately improve parental adherence to PECS recommendations.

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Appendices

Appendix A: Letter of Invitation to Clinicians

Faculty of Social Sciences
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Letter of invitation to clinicians

Dear Clinician,

We are conducting a study to investigate clinical services, such as Speech Language Pathology (SLP) and Behavioral Therapy (BT) delivered to families of children with a Developmental Disability (DD) and/or Autism Spectrum Disorder (ASD). Often clinicians recommend strategies to parents/caregivers to implement augmentative and alternative communication devices to increase functional speech for their children. The purpose of this study is to investigate factors that contribute to parental adherence to clinician supports and to provide recommendations to improve direct service delivery for speech language and behavioral services.

As a clinician that has used the mediator model of service delivery, we would like to invite you to participate in this study. Four focus groups will be held, and you will be invited to attend whichever group is most convenient for you. *Free parking and refreshments will be provided. All clinicians will be given $50.00 in appreciation of their time and effort.*

If you agree to take part in this study, you will be asked to participate in a 2 hour focus group with other clinicians who have agreed to participate. During the focus group you will be asked to share your experiences regarding families and talk about what recommendations seem easy or difficult for parents to adhere to and implement. You will also be asked to suggest ways we can improve parent adherence to clinician supports on Picture Exchange Communication System (PECS) implementation.

All focus group discussions will be kept CONFIDENTIAL.

Attached is the consent form, which includes further details about the study and your participation. If you have any questions, please contact me at 905 688 5550 ext. 5675 or 1-877- 688- 8131.

Thank you for considering this request,

Dr. Rosemary Condillac, Principal Investigator/Faculty Supervisor

Appendix B: Informed Consent Form

Faculty of Social Sciences
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Informed Consent Form for Clinicians

Date: April 12, 2012
Project Title: Bridges and Barriers to the implementation of Picture Exchange Communication System (PECS): An evaluation

Principal Investigator/Faculty Supervisor:
Dr. Rosemary Condillac
Department of Centre of Applied Disability Studies
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Student Investigator:
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Invitation & Purpose of the Study

We would like to invite you to participate in a research study. Many clinicians including, speech language pathologists (SLP) and Behavior Therapists (BT) use a mediator model of service delivery. We are interested in learning about the factors that make it easier or more difficult for parents to adhere with clinician recommendations on the implementation of the Picture Exchange Communication System (PECS). We plan to identify the bridges and barriers to adherence of clinical recommendations for families to further understand and develop strategies to improve service delivery.

Procedure

We will hold 2 focus groups with all clinicians who agree to participate in this study. During these focus group we will discuss factors and issues related to good and poor follow-through with clinician supports. We will also develop recommendations to improve parent follow-through with clinician strategies. The focus groups will be approximately 2 hours in length and will be audio recorded. We are also going to hold 2 focus groups with parents who use the Picture Exchange Communication System with their child to discuss the same issues from a parent's perspective.

Risks and Benefits

We do not anticipate any risk to the participants in this study. This study simply involves talking with parents and clinicians about their beliefs about follow-through with clinician recommendations. We will do our best to maintain a positive and open atmosphere during the focus group and will provide breaks and snacks as necessary.

This study may teach us about the bridges and barriers to clinician supports of implementing PECS and help us to design strategies to improve parent adherence. Outcomes of this study may influence speech language and behavior therapy services and therefore have the potential to improve future service delivery, involving parents.

Privacy, Confidentiality & Safe Handling of Information

We will make every effort to maintain your privacy and confidentiality throughout the study. Specific information about you will only be seen by those directly involved with this research. There is a risk that people who participate in the focus groups will disclose information about the people and discussions involved. We will ask everyone that participates in the focus groups keep all discussions and individuals present confidential. All information and study materials will be stored safely at Dr. Condillac's lab at Brock University in St. Catharines and/or in her Toronto office.

Results of this study will be distributed through a report available on Dr. Condillac's website and through submission to local and international conferences, and journal submissions. Summaries of the research findings will provide group and individual results without identifying information. When presenting the results of this research, we will never use your name or identifying information without your express written permission.

Participation

Your participation in this study is completely voluntary. You are free to decide whether or not you agree to participate in this study. Even if you consent to participate, you can later withdraw. Your decision to participate or not to participate or to withdraw is strictly voluntary.

Should you have any questions about the study, please contact Dr. Rosemary Condillac (905) 688-5550 ext. 5675 or 1-877- 688- 8131

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # 10-107-CONDILLAC. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.
Thank you for your assistance in this project. Please keep a copy of this form for your records.

Consent Form

I, _____

- have read and understand the description of the Bridges and Barriers research study and have been given the opportunity to ask questions and get additional information.
- understand that focus groups will involve other individuals involved in the study and all participants will be asked to keep discussions from the focus groups confidential. I understand that the focus groups will be audio taped.
- understand that I can choose freely whether or not I will participate in this study. The potential risks and benefits of this study have been explained to me. I know that I can withdraw from the study at any time.
- am aware that I can continue to ask any questions that I might have about the study, including asking to see the transcription of comments from the group that I attended.
- understand that the focus group will be audio taped and then later transcribed (typed out)
- have been assured that all information collected as part of the study will be held in strictest confidence, unless required by law (e.g. information regarding abuse or neglect is disclosed). I understand that when results are shared in papers or presentations, information that could identify myself will not be included.
- give permission for Dr. Rosemary Condillac to use the information collected in this study as part of future studies. I understand that personal and identifying information will not be used in future studies, as it is not used in the current one.
- understand that the results of this study may be published or presented, but that my anonymity would be protected in these circumstances.

Any specific concerns or exceptions to my consent are as follows:

❑ I would like to receive a summary of the final results of the study.

_____ _____
Signature Signing Date

_____ _____
Witness Signing Date

Appendix C: Basic Demographic Form

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Basic Demographic Form for Clinicians

1. What is your age?

2. Is English your first language? If not, can you communicate without an interpreter?

3. Where do you work?

4. What type of work do you do? What is your role?

5. Have you provided a parent of a child with Autism or Developmental Disability (DD) recommendations to use Picture Exchange Communication System (PECS) at home?

Appendix D: Focus Group Script

Faculty of Social Sciences
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Focus Group Script for Clinicians

Categories of Questions (Krueger & Casey, 2000)	**Focus Group Questions**	
Opening questions	**30 sec per person**	**5 min**
• Get people talking • All participants answer this question • Easy to answer quickly • Facts not attitudes and opinions • Typically aren't analyzed	1. Tell us your name, how long you've been a behavior therapist, and what kind of work that you do?	
Introductory questions	**5 min discussion**	**10 min**
• Introduce the topic • Get people to start thinking about their connection with the topic • Allow participants to tell about how they see or understand the issue	2. What is the first thing that comes to mind when you think of parent follow-through with recommendations in general?	
Transition questions	**5 min each question**	**20 min**
• Participants become aware of how other view the topic • Set the stage for productive key questions • Make connection b/w the participant and the topic	3. When you first meet parents, what do they think the mediator model is and what do they expect from you as a behavior therapist? 4. What do you consider good and poor follow-through?	
Key Questions	**15 min each question**	**95 min**
• Drive the study • Require the greatest attention and analysis • 10 – 20 min discussion per question • 2-5 questions	5. What do you think parents expect from behavior therapy services? 6. What types of PECS recommendations seem easy for parents to implement? And what types of PECS recommendations seem difficult for parents to implement?	

	7. What factors do you think lead to or contribute to good follow through… on implementation of PECS? 8. What factors do you think lead to or contribute to poor follow…. through on the implementation of PECS? 9. How does lack of follow-through impact the work you do with clients? 10. Have any parents given feedback on what they found helpful or unhelpful? If so, have you incorporated it into your training?	
Ending questions	**25 min discussion**	**120 min**
• Bring closure to the discussion • Enable participants to reflect on previous comments • Critical to analysis 1. The all things considered questions 2. The summary question 3. The final question	11. What are some things that can be done to enhance follow-through in the future? 12. What would be the ideal situation to optimize parental adherence to recommendations on PECS? *give a short 2-3 min oral summary of discussion* 13. Is that an accurate summary? 14. Is there anything that we should have talked about that we didn't?	